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ABSTRACT

This report of the National Council on Disability (NCD) examines root causes of the crisis in mental health, specifically the dysfunction of fragmented public systems charged with providing mental health services and supports for children, youth, adults, and senior citizens diagnosed with mental illnesses. Following an introductory chapter, chapter 2 provides background information. Chapters 3, 4, and 5 look specifically on the effect of mental illness and service failures on children and youth, adults, and seniors, respectively. Chapter 6 presents 13 recommendations. For children and youth, these include expanding Medicaid coverage to children and youth with emotional disturbances through the use of waivers and options; preventing exclusion from school of children with emotional disturbances; and using existing entitlement programs to prevent involvement with the juvenile justice system. For adults and seniors, recommendations include providing a legally enforceable right to mental health services and supports and amending insurance laws to end practices that discriminate against persons with mental illness. Chapter 7 offers an inter-generational vision for effective mental health services and supports that focuses on improving access and reducing barriers to needed services and promoting recovery. An appendix presents the mission statement of the NCD. (Contains 71 references.) (DB)

The Well Being of Our Nation: An Inter-Generational Vision of Effective Mental Health Services and Supports



National Council on Disability
September 16, 2002

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1331 F Street, NW, Suite 850
Washington, DC 20004

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Executive Summary

At a time when more is known about mental illnesses than at any other time in history and just three years after the U.S. Supreme Court held that unnecessary institutionalization violates the Americans with Disabilities Act, public mental health systems find themselves in crisis, unable to provide even the most basic mental health services and supports to help people with psychiatric disabilities become full members of the communities in which they live.

This report does not aim to be a comprehensive review of all that is known about public mental health and its shortcomings. That undertaking has been begun by the U.S. Surgeon General, in the massive 1999 report entitled *Mental Health: A Report of the Surgeon General* (<http://www.surgeongeneral.gov/library/mentalhealth/home.html>), and will be carried on with President Bush's New Freedom Commission on Mental Health, which held its first public hearings in July 2002. Rather, this report examines some of the root causes of the crisis in mental health, and seeks to "connect the dots" concerning the dysfunction of a number of public systems that are charged with providing mental health services and supports for children, youth, adults and seniors who have been diagnosed with mental illnesses.

One of the most significant findings of this report is that children and youth who experience dysfunction at the hands of mental health and educational systems are much more likely to become dependent on failing systems that are supposed to serve adults. In parallel fashion, adults whose mental health service and support needs are not fulfilled are very likely to become seniors who are dependent on failing public systems of care. In this fashion, hundreds of thousands of children, youth, adults and seniors experience poor services and poor life outcomes, literally from cradle to grave.

There is no single antidote for the current dysfunction of the public mental health system. Clearly, visionary leadership, adequate funding and expansion of proven models (including consumer-directed programs) are essential ingredients. More than these, however, there needs to be a dramatic shift in aspirations for people with psychiatric disabilities.

Public mental health systems must be driven by a value system that sees recovery as achievable and desirable for every person who has experienced mental illness. Systems also must commit to serving the whole person, and not merely the most obvious symptoms. In other words, mental health systems will have to develop the expertise to deliver not just medication and counseling, but housing, transportation and employment supports as well.

There are proven models of success throughout the country, but entrenched forces and stale thinking have prevented them from “going to scale” to serve more people with psychiatric disabilities. Some such models are referenced throughout the report, and Chapter 6 provides a menu of concrete actions to bring about a new vision of public mental health services and supports.

Chapter 1

Introduction

For decades, state mental health systems have been burdened with ineffective service-delivery programs and stagnant bureaucracies. Their operations have become rote, spurred to change only by crises. Combined with ever-increasing fiscal pressures, this situation has precluded innovation and kept most systems from incorporating the new and more effective interventions developed in recent years. As a result, state mental health systems have all but disintegrated, falling ever farther from the ideal of voluntary, accessible and effective services and supports that promote meaningful community membership.

As large state psychiatric hospitals have been downsized or closed over the past 30 years, people with psychiatric disabilities, advocates, providers and policy makers have learned that recovery from mental illness requires much more than traditional “mental health services.” Rather, recovery may require access to housing, transportation, employment and peer supports and, for certain individuals, these may be much more important than medication, therapy and case management. Yet, with rare exceptions,¹ mental health systems have been slow to acknowledge and respond to these needs with meaningful, naturalistic supports. Throughout this report, reference will be made to “mental health services and supports” to highlight the critical importance of each in providing the tools that a person with a psychiatric disability may need to recover from symptoms of mental illness, to overcome isolation and to gain (or regain) economic self-sufficiency.

A growing number of advocates, policymakers and members of the media have

¹ Vermont has secured a “Medicaid 1115 Waiver” to allow it to provide flexible and comprehensive services and supports through its Community Rehabilitation and Treatment (CRT) program, and has devoted state funding to provide housing and other services not reimbursable under Medicaid. As a consequence, each of the 3,200 adults in the CRT program has access to a broad range of supports that are tailored to his or her specific needs. See Department of Developmental & Mental Health Services, DESCRIPTION OF PROGRAMS AND SERVICES, at <http://www.state.vt.us/dmh/>

begun to realize that the public mental health system² in most states is highly dysfunctional, and rations care in a manner that requires people with serious mental illnesses to “hit bottom” before receiving the services and supports they need to live successfully in the community³. The depressing reality is that this approach is shared by systems serving children, youth, adults and seniors, creating dependency and perpetuating failure, sometimes literally from cradle to grave.

In fact, the use of the term “mental health system” is, itself, problematic. One of the primary problems is that states do not have a single system of mental health care, but a number of patchwork systems that are called upon to provide such care, often without a guiding vision of how to do so most effectively and frequently without the funding to actually deliver services and support to every eligible person. To be diagnosed with a mental illness (or with “severe emotional distress,” the term applied to children and youth under the age of 18) is to be consigned to one dysfunctional system after another. In fact, the evidence shows that once the label has been applied and a person has been failed by one public system, chances are high that he or she will frequently be failed by other systems as well.

Throughout the 1970s, 1980s, and 1990s, whether in times of budgetary deficit or surplus, states failed to adequately fund their mental health systems. But the pressing needs

² The term “public mental health system” refers to the system(s) of care in a state that serves individuals and families that are poor. The public mental health system provides more than half of all funding for mental health services in America. While for health care, private insurance is a major payer, the private system contributes only 46 percent for mental health, and its role is shrinking. See Health Care Plan Design and Cost Trends: 1988 through 1997, The Hay Group, Washington, D.C. 1998. This paper focuses solely on the public systems charged with providing mental health care and supports to poor people.

³ See, e.g., Bazelon Center for Mental Health Law, *Disintegrating Systems: The State of States' Public Mental Health Systems* (December 2001); Abigail Trafford, “Second Opinion: Writing Off Depression,” *The Washington Post*, Tuesday, January 1, 2002; Page HE01.

of people with mental illnesses did not just disappear. They were forced underground or, more accurately, they were forced onto other public and private systems that were not designed to provide mental health services and supports.

In many communities, jails and prisons become the safety nets and the largest providers of mental health services. Homeless shelters and nursing homes have become housing of last resort for people with mental illnesses. Hospital emergency rooms have provided crisis-oriented care for a few days at a time before sending people with mental illnesses back into a community setting where they are destined to fail because of a lack of mental health services and supports.

When children and youth with severe emotional disturbance cannot get the family-based care and supports they need, they often end up in foster care or juvenile justice, and may be consigned to institutional settings where they are further cut off from their natural support systems. Seniors with unmet mental health needs are often relegated to nursing homes or unregulated "board and care" homes where they are left to fend for themselves.

While they do not appear on the budget line for the state mental health agency, the costs of care for people with mental illnesses are borne by these other systems (and by taxpayers). Typically, these costs are many times higher than what it would cost to provide modest, preventive services and supports, such as counseling, peer support, respite care, supportive housing and job training.

Beyond funding, one of the most significant barriers to access is that, outside of psychiatric hospitals, the public mental health system is only "open" from 9 a.m. to 5 p.m. By contrast, law enforcement, jails and prisons, emergency rooms, homeless shelters and other systems are "open" 24/7 and, as a consequence, have ended up taking a larger share of people in crisis.

Through neglect or underfunding, the public mental health system in many states has

effectively closed its doors, through the use of waiting lists, priorities for service, and disqualification of people who are thought to be “hard to serve” or “treatment resistant.” As a consequence, adults with mental illnesses have increasingly found themselves caught up with law enforcement, the judicial system and the correctional system.⁴

Children and youth with severe emotional disturbance are also shunted from system to system, without adequate care from any of them. Even where they have a legal entitlement to services—such as Medicaid’s Early Periodic Screening, Diagnosis and Treatment (EPSDT) program or the right to a “free and appropriate public education” under the Individuals with Disabilities Education Act (IDEA)—enforcement of these entitlements is problematic because of a shortage of knowledgeable attorneys willing to take on such claims.

When families can’t enforce their children’s right to services and supports designed to keep them at home (or when they run out of private insurance benefits), they are often forced to relinquish custody to the state, which then provides fully-funded Medicaid services to secure services very similar to those that had been denied to families, or had been difficult for families to access.

As a result of all these shortcomings, people with psychiatric disabilities, family members, advocates and members of the general public have extremely low expectations of the mental health system, and even these are often frustrated.

This paper is designed to provide a broad overview of the current state of public systems charged with providing mental health services and supports to children, youth, adults and seniors and to identify, across these age groups, common trends that have led to the failure of these public systems. It will do so by examining the following themes:

⁴ See, e.g., Criminal Justice / Mental Health Consensus Project, at <http://www.consensusproject.org/>. “Life on the Outside,” *All Things Considered*, May 30, 2000, available at <http://www.npr.org/ramfiles/atc/20000530.atc.06.rmm> (Cook County Jail is Illinois’ biggest mental health facility).

- Mental health systems are focused on crisis and on those “most in need,” requiring that people with psychiatric disabilities “hit bottom” before getting the services and supports they need;
- Missed opportunities for prevention: The failure of community-based and preventive systems leads to greater reliance on isolating institutions and segregated “residential placements”;
- Despite clear eligibility, many people are denied mental health services and supports, or find them entirely inaccessible; and
- The failure to provide timely, voluntary and effective mental health services and supports leads to tragic consequences for people with psychiatric disabilities and for society at large.

Chapter 2

How Did We Get Here?

Since the early 1960s, national policy on serving people with serious mental illnesses has focused on reducing costly and often neglectful institutional care and relying, instead, on providing services more humanely in the community. This movement acquired the unwieldy title of "deinstitutionalization." One impetus in the early 1970s was the landmark decision in the case of *Wyatt v. Stickney*,⁵ which established a constitutional right for people confined in state mental institutions to receive treatment for the condition that led to their confinement, rather than being merely warehoused.

In the landmark *Olmstead* decision (*Olmstead v. L.C.*, 119 S.Ct. 2176, 2188 (1999)), which reaffirmed the ADA's integration mandate, the Supreme Court stated that "*Unjustified segregation in an institution...is properly regarded as discrimination based on disability.*" Moreover, in her majority opinion, Judge Ruth Bader-Ginsburg observed that: (a) "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and (b) "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." The decision makes clear that the ingrained neglect of public systems constitutes a violation of civil rights. It compels states to consider how their systems of care perpetuate needless segregation and its harmful effects.

Despite many court orders and legislative pronouncements, however, the ambitions of deinstitutionalization have yet to be realized. There is no comprehensive community-

⁵ 344 F.Supp. 387, 391 (M.D. Ala.1972), aff'd sub nom. *Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974).

based service systems that were deemed necessary for people with psychiatric disabilities to thrive as they returned home. Lacking access to the services and supports that promote self-sufficiency, adults with serious mental illnesses such as schizophrenia, bipolar disorder and major depression, and children and youth with emotional disturbance remain vulnerable to homelessness, frequent re-hospitalizations, unemployment and involvement with criminal justice systems.

Access to Services Through Public Programs

People who either do not have private health insurance or exhaust their coverage must turn to public-sector mental health programs. Unfortunately, shrinking public-sector resources means that most of the uninsured are unable to get the services and supports they need. They are given what is available—often no more than a bimonthly appointment with a psychiatrist and a supply of medication meant to suppress symptoms. In this fashion most people with psychiatric disabilities who are poor are merely being “warehoused” in the community rather than being helped toward recovery and independence.

Federal Medicaid law requires that all covered children and youth have access to all medically necessary services, through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate. But many states do not adequately implement EPSDT, nor do they require their managed care contractors to do so.⁶ Medicaid law prohibits reimbursement to psychiatric hospitals for non-elderly adults. It does, however, permit states to cover a full array of comprehensive community-based services. Yet many states have failed to use these options, leaving some, particularly adults with serious mental illness, without access to the array of effective services detailed in the Surgeon General’s report, such as targeted case management and psychiatric rehabilitation, let alone help with housing, transportation and employment.

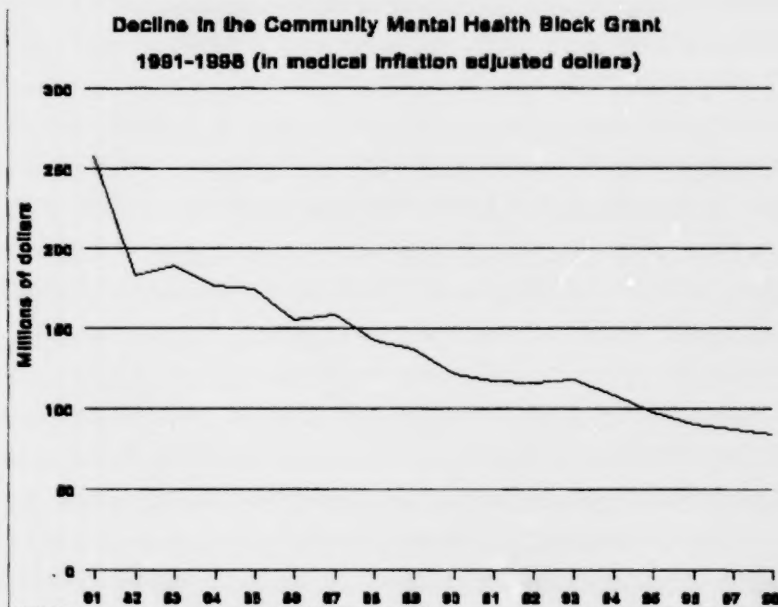
⁶ *Where to Turn: Confusion in Medicaid Policies on Screening Children for Mental Health Needs*, Bazelon Center for Mental Health Law, 1999.

Children, youth and adults with the most serious forms of mental disability are victims of neglectful public systems that preclude their access to the resources necessary for stable lives and meaningful participation in the community. They are further victimized when the consequences of unmet needs are punitive—for example, when they are arrested for behavior, such as sleeping on the street, that is an outcome of their lack of access to housing and mental health services.

Federal Mental Health Block Grant. The Federal Government, through the Supreme Court's ruling in *Olmstead* has clarified the duties of states to provide appropriate community services in lieu of institutional care for people with mental illness. It would be appropriate, at this time, for the Federal Government itself to increase its financial contribution to spending on community mental health services through the major mental health services program, the Community Mental Health Services Block Grant.⁷

Over the past 18 years, federal appropriations for the mental health block grant have fallen in real terms. In 1980, community mental health centers received \$293 million in annual federal appropriations—a small amount in overall mental health spending, but nonetheless an important proportion of the resources available for community care. However, even that modest amount looks significant today. In 1981, when the community mental health law was repealed and the mental health block grant was enacted to replace it, spending was reduced 14 percent. Following this substantial cut, the block grant has continued to drastically lose ground to inflation, as the graph below illustrates.

⁷ The Center for Mental Health Services' Community Mental Health Services Block Grant awards grants to the States to provide mental health services to people with mental disabilities. Through the Community Mental Health Services Block Grant, a joint Federal-State partnership, CMHS supports existing public services and encourages the development of creative and cost-effective systems of community-based care for people with mental disabilities. With the current changes in the health care delivery system, improving access to community-based systems is especially important. See <http://www.mentalhealth.org/publications/allpubs/KEN 95-0022/default.asp>.



(Source: Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses*)

The Federal Government could, and should, do more to assist states in meeting the needs of individuals who are unnecessarily institutionalized or at risk of unnecessary institutionalization. In January 1999, the administration requested that Congress increase appropriations for the mental health block grant by \$70 million. Such an increase, while helpful, is far short of the level needed to restore lost spending power for the block grant. Advocates should urge the administration and the Congress to increase federal appropriations for the block grant to \$1 billion. This would raise spending on mental health to a level more commensurate with spending under the substance abuse block grant (\$1.585 billion).

Inadequate federal funding is exacerbating a crisis in community mental health at the state and local levels, where budget shortfalls are leading to drastic cuts in vital mental health programs. The landmark report on mental health issued by the Surgeon General of the United States in December 1999 affirmed that the technology exists to provide effective treatment—even to people with serious mental illnesses. The problem is that these treatments are simply not

accessible to all who could benefit from them.

State Appropriations

Community mental health services are generally no more expensive than institutional care. However, to shift a system from over-reliance on institutions to one that provides more appropriate and more effective community services and supports requires an investment in the community. Start-up costs, along with the need to ensure that people continue to receive care while new community options come on line, have hampered states' ability to ensure that resources follow individuals into the community. Until community services are up and running, Medicaid and other sources of reimbursement cannot be tapped. Accordingly, states may need to make a direct appropriation of their general funds for this purpose.

But far from meeting these obligations, states have been reducing spending on mental health services over past years. For example:

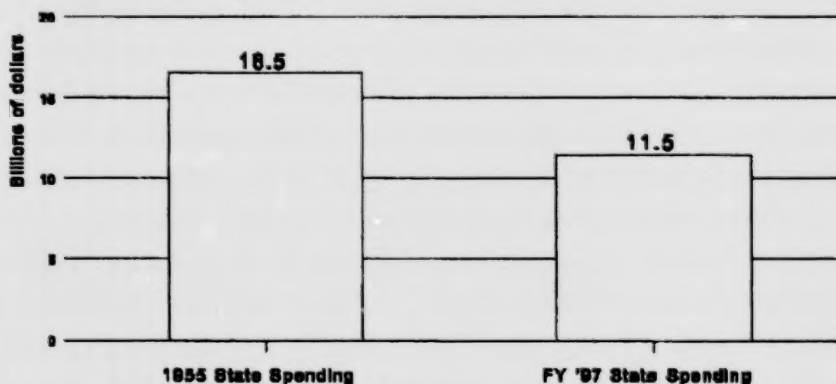
- State only appropriations for mental health services are significantly lower today (adjusted for inflation and growth in population) than they were in 1955, when most people with mental illness were warehoused in state institutions.⁸ Given that institutions provided little in the way of real treatment at that time, it would be expected that state expenditures for mental health would have grown, as new and effective approaches to care and supports were developed.
- State appropriations for mental health have lost ground, by 7 percent, between 1990 and 1997. This is true for nearly every state, as shown in the comparison of states adjusted for inflation in the table below.

⁸ Note: State spending figure includes state and local appropriations for mental health and excludes the federal match for Medicaid, the federal mental health block grant, first- and third-party payments and other non-state sources. Lutterman, T., Hirad, A. and Poindexter, B., *Funding Sources and Expenditures of State Mental Health Agencies, Fiscal Year 1997*, National Association of State Mental Health Program Directors Research Institute, Inc. Alexandria, VA. 1999, Table 23.

- State appropriations for mental health have been falling in relation to other state spending. Spending on mental health has grown more slowly than (1) total state-government spending, (2) state-government spending on health and welfare and (3) spending on corrections.⁹ During the 1990s, state mental health spending grew by 33 percent, but total state spending grew 56 percent, spending on health and welfare services grew by 50 percent and spending on corrections, by 68 percent.

The overall change in real purchasing power for state mental health appropriations between 1955 and 1997 is shown in the chart below. While other funds supplement these state expenditures (for example, the federal Medicaid match and the federal mental health block grant), these falling numbers represent a reduction of states' own efforts over the years.

**Comparison of State Commitment to Mental Health
1955 (adjusted for medical inflation and population) and 1997 Spending**



(Source: Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses*)

Accordingly, it would hardly be a fundamental alteration in programming for states to increase their appropriations for community mental health services in order to comply with the Supreme Court's ruling in *Olmstead*. Investment in community services has the potential to bring about long-term savings by enhancing states' ability to tap into federal dollars, making increased investment in developing community services and supports even

⁹ *Id.*

more important.

Chapter 3

Impact on Children and Youth

Crisis Focus

As is well documented elsewhere,¹⁰ children with emotional disturbance experience significant gaps between the systems of care designed to serve their needs and to support them with their families and in the community. Due to the stresses of poverty, children and youth from low-income families are disproportionately represented among young people diagnosed with emotional disturbance. While this labeling theoretically entitles children to a wide range of services and supports, these are often not delivered. In addition, the labeling itself may serve to reinforce a view of these children as dysfunctional, and relegate them to segregated settings. Public policy must seek to reduce this stigma while delivering supports and services (including naturalistic supports, such as mentoring, after-school programs and improved housing).

The Substance Abuse and Mental Health Services Administration (SAMHSA) estimates that 20 percent of all children from birth to 17 years of age suffer from a diagnosable mental, emotional or behavioral illness.¹¹ According to SAMHSA, approximately 7 million children had a diagnosable mental disorder in 1997. Between children and adolescents aged 9 to 17, SAMHSA estimates 2.1-4.1 million (five to 13 percent) have a mental or emotional disorder that seriously impairs their functioning in day-to-day activities.

¹⁰ National Council on Disability, *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves*, available at <http://www.ncd.gov/newsroom/publications/privileges.html#5>, at Chapter 5;

Bryant, E. S., Rivard, J. C., Addy, C. L., Hinkle, K. T., Cowan, T. M., & Wright, G. (1995). Correlates of major and minor offending among youth with severe emotional disturbance. *Journal of Emotional and Behavioral Disorders*, 3 (2), 76-84.

¹¹ Mental Health Needs Of Many U.S. Children Going Unmet, available at <http://www.pslgroup.com/dg/4D1FA.htm>.

America's youth is the human resource capital of America's future. The value of these human resources is incalculable. We cannot define or put a value on the loss incurred when today's children and youth with emotional disturbance are damaged in their formative years by systems' failures to provide needed mental health care and/or special educational services. For example, children who lack these services often cannot utilize the free and appropriate public education to which they are entitled under federal law. Children with unrecognized or untreated emotional disabilities cannot learn adequately at school or benefit readily from the kinds of healthy peer and family relationships that are essential to becoming healthy and productive adults.

Many young people with emotional disturbance are already involved in the juvenile justice system.¹² Rates of emotional disturbance among youth in the juvenile justice system have been estimated at 60-70 percent. A significant percentage of the 100,000 youth detained in correctional facilities each year suffers from serious mental disabilities and a commensurately large percentage suffer from addictive disorders. Seventy-five percent of the youth in the juvenile system have conduct disorders and more than half have co-occurring disabilities.

According to a 1999 report by Substance Abuse and Mental Health Services Administration, when compared with adolescents having fewer or less serious behavioral problems, adolescents with behavioral problems such as stealing, physical aggression, or running away from home were seven times more likely to be dependent on alcohol or illicit drugs.

While major mental illness, such as schizophrenia, is often evident only when the individual reaches the late teens or early twenties, there is little doubt that many other disabilities found among the adult prison population surfaced at a much younger age—and went untreated.

The failure to identify (and treat) emotional disturbances is also associated with the

¹² See, e.g., Children's Defense Fund, Quick Facts: Mental Health and Juvenile Justice (CDF), at http://www.childrensdefense.org/ss_jjfs_menthlthjj.php

growing problem of teen suicides and/or suicide attempts. If properly implemented, Medicaid's EPSDT screening program should assist parents of youth with emotional disturbance and school personnel in identifying their disabilities, providing the appropriate treatment, and preventing suicide.

The lack of home- and community-based services has still other negative consequences. The lack accounts for unnecessary hospitalization of children and youth with emotional disturbance. It also contributes to readmission. For lack of services that might ease the transition from hospital to home, including respite services for their families, these children cycle back and forth between hospital and the community without ever achieving stability. In turn, unnecessary hospitalization usurps the limited resources of state mental health budgets, thus obstructing the provision of services that might have prevented institutionalization and perpetuating an unproductive cycle.

If all aspects of the system—from assessment to treatment—took into account the long-term needs of children, rather than episodic or crisis occurrence, children's needs would be described in terms of their underlying issues and in the context of their family and living situation instead of mere documentation of short-term behavior or services available. For some children, the system must be prepared to make a commitment to serve the child for their entire childhood, with easy entry and re-entry into the system. Outcome measures should reflect long-term goals—such as school attendance, living at home with family or independently, and working at a job.

Missed Opportunities for Prevention

Poor treatment by the system as a child or youth increases the likelihood of encountering other dysfunctional systems as an adult. Children with serious emotional disturbance have the civil right to receive services in the most integrated setting appropriate to their needs.¹³ They

¹³ The U.S. Supreme Court stated that individuals have such a right unless the state

further have the human right to be raised in their families and communities, with their individual needs guiding the service array provided. These civil and human rights are embodied in the Americans with Disabilities Act (ADA).¹⁴

The failure to identify and treat mental disabilities between children and youth has serious consequences, including school failure, involvement with the justice system and other tragic outcomes. As outlined in the Adult chapter, below, adults with mental illnesses who find themselves in the criminal justice system are significantly more likely to have grown up in foster care, under custody of a public agency or in an institution.

There are large discrepancies between the mental health needs of children and youth and the services they actually receive. A recent study found that only one in five children with emotional disturbance used any mental health specialty services, and a majority received no mental health services at all. This is consistent with an earlier finding by the Office of Technology Assessment (OTA) which estimated that only 30 percent of the 7.5 million children who needed mental health treatment received it. However, children with serious emotional disturbance often do not receive the services to which they are entitled under the Individuals with Disabilities Education Act (IDEA).

Individuals with Disabilities Education Act: IDEA has long been the primary vehicle for securing mental health services and supports for children and youth with mental, emotional or behavioral disabilities. The Act's basic tenet is that, until age 21, children and youth are entitled to "a free and appropriate public education." Under IDEA, children with emotional or

can show that implementation would be a fundamental alteration. *Olmstead v. L.C.*, 119 S.Ct. 2176, 2188 (1999).

¹⁴ Children also have rights under the Individuals with Disabilities Education Act (IDEA), including the right to services in the least restrictive setting appropriate for the child. See, generally, Bazelon Center for Mental Health Law, *Olmstead Planning for Children with Serious Emotional Disturbance: Merging System of Care Principles with Civil Rights Law*, available at <http://www.bazelon.org/olmsteadchildren2.pdf>

behavioral disabilities that interfere with their ability to learn are entitled to special education services, including any related mental health services and supports that enable them to benefit from their education. Yet despite the intent of this strong federal entitlement, parents and advocates report that children are not receiving many of the promised and needed services. Children and youth with emotional and behavioral disabilities are the least likely to receive the services and supports mandated by IDEA.

The 1997 IDEA amendments mandated that school systems provide two new services to address the needs of children and youth with behavioral problems that interfere with their learning or the learning of those around them. Schools must conduct "functional behavioral assessments" (FBA) to determine the causes of undesirable behavior and develop "positive behavioral interventions and supports" (PBIS) to address them. According to Robert Horner, Ph.D., of the University of Oregon faculty,

"research conducted over the past 15 years has demonstrated the effectiveness of strategies that foster positive behavior for individual students and for entire schools. Even schools with intense poverty, a history of violence and low student skills have demonstrated change in school climate when effective behavioral systems have been implemented."

Despite this history of success, parents and school personnel report that schools are not implementing the provisions of the 1997 IDEA amendments. Some profess they don't understand the statute; others are ignoring or actively subverting the law. In almost all cases, it is apparent that school personnel are unaware of how effective (and relatively inexpensive) these interventions can be.

EPSDT and Medicaid: Medicaid-eligible children should also benefit from the early screening required under the Medicaid's Early Periodic Screening, Diagnosis and Treatment (EPSDT) mandate and a generally broader array of services in state Medicaid plans than is available in the private sector. Under EPSDT, all states must screen Medicaid-eligible children,

diagnose any conditions found through a screen and then furnish appropriate medically necessary treatment to "correct or ameliorate defects and physical and mental illness and conditions discovered by the screening services."¹⁵

Children and youth up to age 21 have a broader entitlement than adults who qualify for Medicaid. For adults, some services are mandatory, but some need only be provided at a state's option. A state will list its "optional" services in its Medicaid plan, but must make available to children all services listed in federal Medicaid law "whether or not such services are covered under the state plan."¹⁶ Few states have good tools to identify children with mental health needs and most fail to monitor providers or health plans to ensure that children receive behavioral health screens.

Medicaid's EPSDT program, especially when used in conjunction with IDEA, is the ideal vehicle for meeting the comprehensive mental health needs of children and youth. The program requires that states conduct regularly scheduled examinations (screens) of all Medicaid-eligible children and youth under age 22 to identify physical and mental health problems. If a problem is detected and diagnosed, treatment must include any federally-authorized Medicaid service, whether or not the service is covered under the state plan. If problems are suspected, an "inter-periodic" screen is also required so the child need not wait for the next regularly scheduled checkup.

Child mental health services under Medicaid have undergone considerable change over the past decade. For many years, states had included more comprehensive mental health benefits for adults than for children and youth. After the enactment of legislation requiring coverage of all Medicaid-covered services for children through the Early Periodic Screening Diagnosis and Treatment (EPSDT) mandate in 1990, states began revising their rules and expanding coverage of child mental health services.

¹⁵ 42 U.S.C. §1396d(a).

¹⁶ Social Security Act, Section 1905(r)(5). See also, Omnibus Budget Reconciliation Act, 1989, Public Law 101-239.

Shortly after these revisions began to occur, states also began to move the Medicaid population in need of mental health care into managed care, generally into separate “carved-out” specialized managed behavioral health care plans. By 1998, 54 percent of Medicaid beneficiaries were enrolled in managed care programs.¹⁷ (Health Care Financing Administration, 1998). Due to the rapid expansion of covered services early in the 1990s and the subsequent introduction of managed care, it is pertinent to question whether children and youth actually receive these community-based services and to determine the patterns of service use. Key stakeholders continue to cite the lack of attention to the special needs of children and youth as the most serious problem with the public mental health system.¹⁸

By offering waivers and options Medicaid law also affords states other policy choices that could expand access to mental health services. The Home-and Community-based Waiver allows states to provide alternatives to hospitalization to children with disabilities, including children and youth with emotional disturbance. The waiver allows states to provide various community support services, but only three states have availed themselves of this waiver for children with emotional disturbance. Significantly, however, a recent study indicates that the Medicaid home-and community-based waiver is effective in reducing the incidence of custody relinquishment and institutional placement in the three states where they are in use.¹⁹

However, Medicaid does not cover all low-income and other children and adolescents who have no access to mental health treatment. Moreover, while the array of covered services is

¹⁷ <http://www.hcfa.gov/medicaid/trends98.pdf>

¹⁸ Stroul, B. A., Pires, S. A., Armstrong, M. I., and Meyers, J. C. (1998). The impact of managed care on mental health services for children and their families. *The Future of Children: Children and Managed Health Care*, 8, 119-133.

¹⁹ Bazelon Center for Mental Health Law, *Relinquishing Custody, The Tragic Result of Failure to Meet Children's Mental Health Needs*. (Mar. 2000).

fairly broad, some home- and community-based services are still excluded from coverage under many state Medicaid programs.

Denial and Inaccessibility of Services

Despite the IDEA and EPSDT entitlements, children and youth in many states fall through the cracks of the public systems of care. This happens even in states like California, with well-developed local government infrastructure:

“Despite the integrity of individual programs—and even with the extraordinary contributions of so many individual professionals—incremental efforts add up to less than the sum of their parts. The programs often fall short of providing the right services, in the right way, to the right children at the right time. Year after year, new commitments—even with additional funding—fail to achieve the goals so desperately desired.”²⁰

Services are often denied not out of malice, but because of the lack of coordination among systems of care and complexity of funding arrangements:

“Funding is restricted by complex rules that encourage communities to forsake those in the path of danger and focus only on those children who are physically bruised and emotionally broken.”²¹

²⁰ Little Hoover Commission, *Young Hearts & Minds: Making a Commitment to Children's Mental Health*, at iv (Report #161, October 2001), available at <http://www.lhc.ca.gov/lhcdir/report161.html>.

²¹ Id.

Moreover, the criteria that youth must meet before they can receive services can easily be interpreted to deny services.²² In practice, many states do not have specific definitions of all covered services, so it is likely that many Medicaid-eligible children receive neither the mental health screens nor the mental health treatment to which they are entitled by EPSDT. The shortage of knowledgeable legal advocates virtually ensures that the rights of many children to EPSDT services will not be enforced.

Access to services is limited due to lack of insurance coverage for mental health services and inadequate access to the special education and related mental health services for which children and youth are eligible through IDEA. For example, ten million children and youth lack health insurance and many more are under-insured for mental health treatment and exhaust their benefits. An estimated 30 percent (3 million) of those 10 million are eligible for Medicaid, but their families are unaware that they qualify.²³

As states have sought to "do more with less," they have also sought out managed care approaches to limiting Medicaid expenditures. Instead of bridging the gap between child-serving agencies, however, states' shift of Medicaid to managed care has stranded even more children

²² For example, to qualify for special education, the child's mental disability must affect educational performance to a marked degree and over a long period of time. The child must also exhibit one or more of the following characteristics:

- an inability to learn that cannot be explained by intellectual, sensory or health factors;
- an inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
- inappropriate types of behavior or feelings under normal circumstances;
- a general pervasive mood of unhappiness or depression ; or
- a tendency to develop physical symptoms

with serious mental health needs.²⁴

Tragic Consequences for Children, Youth and Society

Custody Relinquishment: Due to lack of community-based services and/or special education services, families of children with emotional disturbance are often faced with the heart-wrenching choice of not receiving adequate mental health services for their children or relinquishing custody of their children in order to qualify for Medicaid. Child mental health advocates and professionals have recognized the issue of custody relinquishment for many years.²⁵

Requiring families to give up custody:

²⁴ Bazelon Center for Mental Health Law, *Managed Behavioral Health Care for Children and Youth: A Family Advocate's Guide* (1996).

²⁵ Jane Knitzer first identified the problem in a ground-breaking 1978 study and elaborated on it in a 1982 publication, *Unclaimed Children: the Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services*. Several later studies confirm Knitzer's findings.

- The Research and Training Center on Family Support and Children's Mental Health found that 25 percent of parents whose children have emotional disturbance received suggestions that they relinquish custody. One third of those parents receiving the suggestion gave up custody in order to get services.
- The Commonwealth Institute for Child and Family Studies conducted a survey of 45 states. In 28 states (62 percent), at least one agency used custody transfer to gain access to state funding for services for children with serious emotional and behavioral problems. Thirty-eight (32 percent) of the responding child-serving agencies used custody transfer to obtain funding for children's treatment.
- The National Alliance for the Mentally Ill surveyed parents of children with mental and emotional disabilities and found nearly one-fourth of them had been told by public officials that they needed to relinquish custody to get needed services for the children.

- traumatizes both children and parents;
- limits family involvement in key decisions about their children's mental health, health and educational needs;
- undermines family integrity;
- unnecessarily burdens public agencies with children who are neither abandoned; nor neglected, but whose families need services and support to raise them at home; and
- penalizes families for the state's failure to develop adequate services and supports.

Requiring families to relinquish custody to the child welfare system in order to obtain essential mental health services and supports for their children wastes public funds and destroys families.

Inadequate funding of mental health services and support for children and their families is the major reason families turn to the child welfare system for help. Private insurance plans often have limits on mental health benefits that can be quickly exhausted if the child has serious mental health needs. In addition, many private plans do not provide the home and community-based services and supports that are needed to keep children at home. When their personal funds run out, families are forced to turn to the child welfare system.

Even families whose children are eligible for Medicaid face custody relinquishment. Although many of the needed services are covered, states fail to adequately define their rehabilitation services, to educate providers on how to bill for those services, or to make sure that Medicaid recipients know the array of services to which a child is entitled. When parents then turn to the child welfare agency, the agency often requires—as a nonnegotiable condition for obtaining those services—relinquishment of custody to the state or county. In large part, this is driven by the child welfare agencies' mistaken belief that custody is required in order to draw federal matching funds under the Social Security Act.

Educational System/Special Education/Discipline: Due to the stresses of poverty, children and youth from low-income families are disproportionately represented in the young population with emotional disturbance. The inequities of the neglect of these children by schools

and the public mental health system are further compounded by racial discrimination.

The failure to provide early screening and mental health services has meant that as many as 35 percent of students entering school are considered to be at high risk for social and academic failure.²⁶ Once in school, the failure or refusal to provide IDEA services results in much greater drop out rates for children and youth with emotional disturbance.²⁷ This has led researchers to recommend a new approach to screening, and to identifying a child's strengths rather than deficits.

In perhaps the classic attempt to blame the victim, school districts that have failed or refused to provide preventive services under IDEA has also led, inexorably, to treating children with emotional disturbance as "discipline problems." In a series of attempts to amend the IDEA over the past three years, Congress has increasingly expanded the authority of school districts to exclude such children and youth from mainstream classrooms.

The techniques for supporting children with emotional disturbance—known broadly as "positive behavioral supports"—in school are well documented.²⁸ The use of punishment to

²⁶ Ruth Goldman, *Model Mental Health Programs and Educational Reform*, *American Journal of Orthopsychiatry*, (1997) p. 347.

²⁷ ABC Project, *Staying in School: Strategies for Middle School Students with Learning and Emotional Disabilities* (1995), at p. 1: "Nationally, 35 percent of students with learning disabilities and 55 percent of students with emotional disabilities drop out of school as compared to about 25 percent of students without disabilities.

²⁸ Among the most recognized of these techniques are to:

- Personalize instruction through accommodating different learning styles and abilities;
- Create leadership opportunities for less-popular students (such as appointing as class helpers);
- Give student alternatives such as self-imposed time-outs, relaxation techniques; and
- Try to eliminate conditions that lead to reactive misbehavior (such as teasing from other students)

correct behavior comes with negative consequences such as negative attitudes on the part of students toward school and school staff (which leads to increased antisocial acts and behavior problems). Punishment of children with emotional disturbance is strongly correlated with dropping out of school.²⁹

Foster care: The child protective services and foster care system in the United States grew out of efforts by early religious and charitable organizations to serve orphans and "rescue" children and youth from abusive or neglectful families. Today's federally supported foster care system was created under the Social Security Act of 1935 as a last-resort attempt to protect children at risk of serious harm at home. The law obligated states to assume temporary custody of children whose parents were unable or unwilling to care for them.

By the early 1990s almost half a million children were in the custody of state child welfare systems and the U.S. Department of Health and Human Services estimated that at least one of every 10 babies born in poor urban areas in the '90s would be placed in foster care.³⁰ Children with emotional or behavioral disabilities made up 40 percent of the child welfare population and few resources were available for any type of treatment or support services.³¹ The steady increase in foster care placements is very troubling. Most children are deeply traumatized when they are separated from their families. Even when their family environment has been dangerous or unhealthy, studies have shown that a child often experiences separation from a primary care giver as a threat to survival.³²

²⁹ Id. at 5.

³⁰ "Proposal to Preserve the Family," Associated Press, *The Wenatchee* (Alabama) *Daily World*, May 24, 1993.

³¹ Mental Health Law Project (now Bazelon Center for Mental Health Law), *The R. C. Case: Creating a New System of Care for Children*, 1991.

³² Firman, C., On Families, Foster Care, and the Pawning Industry, Family Resource Coalition Report, No. 2, 1993.

Family disintegration and allegations of abuse are the most frequent reasons that children are placed in foster care, and these reasons are often rooted in the inability to get mental health services and support for parents and/or children. These findings are documented more fully in the Custody Relinquishment section, above, and are considered further in the Adult chapter, below.

According to the Annie E. Casey Foundation, every year 25,000 young people in foster care turn 18 and leave foster care. This means that young people in state-supervised programs must leave foster care whether or not they have the skills to maintain an apartment, seek and hold a job, or balance a checkbook. Too many 18-year-olds emerge without having had a stable foster-care environment or adequate mental-health services or a quality education. According to one recent study, 12 to 18 months after they left foster care, half of those who left were unemployed and a third were receiving public assistance. Clearly, youths who "age-out" of foster care are among the most vulnerable and the most at risk.

Juvenile Justice: Each year, more than one million youth come in contact with the juvenile justice system and more than 100,000 are placed in some type of correctional facility. Studies have consistently found the rate of mental and emotional disabilities higher among the juvenile justice population than among youth in the general population. As many as 60-75 percent of incarcerated youth have a mental health disorder; 20 percent have a severe disorder and 50 percent have substance abuse problems.³³ The most common mental disabilities are conduct disorder, depression, attention deficit/hyperactivity, learning disabilities and posttraumatic stress.³⁴ According to a 1999 survey conducted by the National Mental Health

³³ Coccozza, J. J. (Ed.) Responding to Youth With Mental Disorders in the Juvenile Justice System. Seattle, WA, The National Coalition for the Mentally Ill in the Criminal Justice System, 1992.

³⁴ Garfinkel, Lili F., Unique Challenges, Hopeful Responses: A Handbook for Professionals Working with Youth with Disabilities in the Juvenile Justice System, PACER

Association (NMHA) and the GAINS Center, mental health problems typically are not identified until children are involved with the juvenile justice system, if at all.

Although African-American youth age 10 to 17 constitute only 15 percent of their age group in the U.S. population, they account for 26 percent of juvenile arrests, 32 percent of delinquency referrals to juvenile court, 41 percent of juveniles detained in delinquency cases, 46 percent of juveniles in corrections institutions, and 52 percent of juveniles transferred to adult criminal court after judicial hearings. In 1996, secure detention was nearly twice as likely for cases involving black youth as for cases involving whites, even after controlling for offenses.³⁵

Many youngsters have committed minor, nonviolent offenses or status offenses. The increase in their incarceration rates is a result of multiple systemic problems, including inadequate mental health services for children and more punitive state laws regarding juvenile offenders. These nonviolent offenders are better served by a system of closely supervised community-based services, including prevention, early identification and intervention, assessment, outpatient treatment, home-based services, wraparound services, family support groups, day treatment, residential treatment, crisis services and inpatient hospitalization.

Intensive work with families at the early stages of their children's behavioral problems can also strengthen their ability to care for their children at home. These services, which can prevent children from both committing delinquent offenses and from re-offending, are most effective when planned and integrated at the local level with other services provided by schools, child welfare agencies and community organizations.

More than one in three youths who enter correctional facilities "have previously received special education services, a considerably higher percentage of youths with disabilities than is

Center, 1997.

³⁵ 1999 National Report Series, *Juvenile Justice Bulletin*.

found in public elementary and secondary schools.”³⁶ Many children with emotional disturbance end up in detention facilities as a result of incidents at school and/or because they fail to receive special education and related mental health services. In addition, many juveniles are released from detention facilities without appropriate discharge services, and end up being re-incarcerated.

Young people with emotional disturbance are punished for the failure of systems designed to protect them. Because schools fail to identify and serve youth with emotional disturbance, these children miss out on much or all of the “free and appropriate public education” to which they are entitled under the federal Individuals with Disabilities Education Act (IDEA), even though IDEA funds services for such children.³⁷

Although IDEA requires educational plans to be in place prior to a young person’s release from juvenile detention, and a well-designed and implemented plan, coupled with connections to the services provided under Medicaid, can mean the difference between a successful transition to home and community or a repeat of the negative cycle that landed the juvenile in detention in the first place, few states implement this requirement. Thus, juvenile offenders with emotional disturbance frequently fail to reconnect with the education system upon their release.

Without the appropriate intervention, students whose behavior could and should be addressed in school are ending up in juvenile detention. Each year over 100,000 youth are

³⁶ “Special Education in Correctional Facilities,” by the National Center on Education, Disability and Juvenile Justice (1990). Available at http://edjj.org/Publications/pub05_01_00.html.

³⁷ Almost always for want of special education services, 55 percent of children with emotional disturbance drop out—more than twice the rate of other students in the general population. Nearly 20 percent of students with emotional disturbance have been arrested, compared with an arrest rate of nine percent for all students with disabilities. As these children age and leave school without adequate preparation or skills, the arrest rate climbs. Of youngsters with emotional disturbance out of school for two years—more than a third had been arrested. By the time they had been out of school for five years, more than 70 percent had been arrested.

detained in correctional facilities. These institutions have been called the “de facto” psychiatric institutions for adolescents with mental health problems because they substitute incarceration for needed treatment. A recent survey by the Pittsburgh Post-Gazette found that 80 percent or more of the residents of Pennsylvania’s juvenile detention centers had a diagnosable psychiatric problem. Arkansas and New Mexico reported that 90 percent of their juvenile detainees were on psychotropic medication.

Effects of Welfare Reform: In the implementation of welfare reform, policy makers have to date focused rather narrowly on the needs of the adult recipients. In particular, reform efforts have concentrated on recipients who are relatively well-positioned to enter the workforce, that is, who do not have evident disabilities or special needs. States have declared remarkable success in their initial efforts to reduce welfare rolls, moving off welfare large numbers of individuals and capitalizing on the current demand for workers. Now, states are beginning to face some unanticipated consequences of return-to-work policies particularly on adults with significant problems (such as those who have mental health and substance abuse issues) and on parents whose children have special needs. States are facing the reality that there is a residual population of welfare recipients whose capacities to work are challenged by these problems.

What might easily be overlooked in the debate on welfare reform is that the children of welfare recipients—both those who have already been counted as “successes” and those remaining on welfare due to special needs—may, themselves, have significant problems. Recipients who have successfully returned to work may have marginal work skills and find themselves in low-level jobs. When they have children with serious emotional disturbance, they may be confronted with parental demands that pull them away from already-precarious work situations. For example, school systems are often ill prepared to deal with special-needs children and seek to exclude them from the classroom. Child care centers are often not prepared to handle children with significant behavioral problems and these children may be expelled, creating significant job-related problems for the parent.

Those welfare recipients who have not yet entered the workforce includes significant numbers of individuals with significant problems of their own, such as depression, post-

traumatic stress disorder, and chemical dependency. These problems among parents have been identified as risk factors for emotional disturbance among their children. The movement of these adults into the workforce, which is already a formidable goal, may pose new problems for their high-risk children. For example, children with serious emotional disturbance who have been reliant on parental care and supervision within the home may, for the first time, be entering child care arrangements outside of the home. These settings must be prepared to offer special approaches appropriate to the needs of these children. In addition, it is likely that the workplace success of recipients who are already struggling to overcome their own problems will be compromised by the added stress of disruptions in their children's functioning.

This array of factors suggests that the special needs of children do not simply coexist with welfare reform; parental return-to-work has both an effect upon these children and is affected by these children. However, few policies thus far have considered the interaction of welfare reform and recipients' children with serious emotional disturbance. Most states have not worked to ensure that the needs of these children are addressed. As the policy and legislative focus comes to be redirected to the hardest to serve welfare recipients (which may well include a significant number of parents of children with special needs), the well being of children will increasingly come to be an issue.

Psychiatric Hospitalization and "Residential Care": Traditionally, the mental health services available to children with emotional disturbance have tended to fall at two ends of a continuum: 1) treatment in a residential facility and 2) individual, usually once-a-week therapy. Yet youth with emotional disturbance need one or more of a broad spectrum of therapeutic modalities between these two poles. These include ongoing intensive services in their home community and school. Additionally, their families need support services, education and training on how to best handle the youngster and his or her problems.

In many cases, the lack of home-and community-based mental health services results in unnecessary institutionalization. Deprived of services, the condition of many children and youth with emotional disturbance worsens and reaches crisis proportions, leaving commitment to a residential treatment facility as the only option. Though residential treatment centers lack studies

supporting their effectiveness, this treatment—which serves a small percentage of youth — consumes one-fourth the outlay on child mental health.³⁸ Referrals to residential treatment facilities—often unnecessary—remove the child far from home and community; sometimes out of the county or even the state for extended periods of time. Moreover, after leaving the hospital, the lack of transitional services and/or intensive in-home services and supports frequently result in children and adolescents cycling from home to hospital and back again without ever achieving stability.

However, effective home- and community-based services—such as in-home services, behavioral aides, intensive case management, day treatment, family support and respite care, parent education and training, and after-school and summer camp programs—do exist. Of these services, the Surgeon General's report found home-based services and therapeutic foster care to have the most convincing evidence of effectiveness.³⁹ These services are furnished in partnership between professionals and families, are clinically and fiscally flexible, and individually tailored for each child and family, providing whatever intensity of service is needed. Home- and community-based services build on strengths and normal development needs rather than just focusing on problems, and provide continuity of care. They strive to be culturally competent and involve the family in the child's care. Evaluations of these community-based services have found them to be highly effective, less costly than the alternative residential services and much preferred by families.⁴⁰

³⁸ U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General* (1999), at Chapter 3.

³⁹ Id.

⁴⁰ Hyde, K. L., Burchard, J. D. & Woodworth, K. (1996). Wrapping services in an urban setting. *Journal of Child and Family Studies*, 5, 67-82; Yoe, J. T., Santarcangelo, S., Atkins, M. & Burchard, J. D. (1996). Wraparound care in Vermont: Program development, implementation, and evaluation of a statewide system of individualized services. *Journal of Child and Family Studies*, 5, 23-38.

Chapter 4

Impact on Adults

Crisis Focus

Every year, youth who have been ill-served by mental health, education and foster care “age out” of those systems and become adults, without the explicit entitlements to mental health and other care they had as youth. Despite the inevitability of this process, the adult mental health system does little to anticipate their arrival, and invests little in programs of prevention. Like the youth-serving systems examined in the last chapter, the adult systems devote very few resources to people until they reach the point of crisis.

For adults, neglect or poor treatment by the mental health system increases the likelihood an adult with mental illness will encounter other more coercive and crisis-oriented systems, like law enforcement, corrections, institutionalization and emergency rooms. Absent the services and supports they need in the community, people with serious mental illness become caught up in the criminal justice system. Ironically, these individuals are often discharged from jails and prisons into the community with little or no planning for treatment. Lacking treatment, their lives become a revolving door of arrest, incarceration, release and rearrest.

With coordination among these systems almost totally lacking, individuals and families living with mental illnesses are faced with a mental health system that swings between the extremes of abject neglect and unwanted intervention, never quite providing the appropriate level of services to sustain them in the community:

- Underfunded systems ration care to those “most in need,” almost guaranteeing that people will be denied services and supports until they are in crisis;
- Without preventive services and supports, most individuals and families living with mental illnesses have difficulty attaining economic self-sufficiency, and

become more dependent on inadequate “safety net” programs like Supplemental Security Income disability and welfare payments;

- Once in crisis, the mental health, criminal justice and correctional systems are primed to respond with coercive measures which tend to undermine the principles of self-determination and consumer direction, and make it harder to achieve recovery and economic self-sufficiency; and
- Crisis-driven services (and monitoring of coercive measures) are dramatically more expensive; they drain resources away from voluntary, preventive services in the community, resulting in long waiting lists and further deterioration of people in need.

By now, it is beyond debate that it is fiscally more prudent to address mental health needs before they reach the point of crisis.⁴¹ But the extraordinarily low priority placed on mental health services, and the “Balkanization” of state budgets virtually ensures that agencies will continue to seek out ways to push “bothersome” clients onto the rolls of other public agencies.

Missed Opportunities for Prevention

Big Investments in Big Hospitals and Precious Little for Community-Based

Services: Historically, mental health systems have devoted a large share of their resources to

⁴¹ See, e.g., Culhane, Dennis, *Comparing The Relative Effectiveness Of Transitional vs. Supported Housing For Single Persons With Severe Mental Disabilities Exiting Homelessness*, Culhane, Dennis, *The Public Costs Of Homelessness Versus Supported Housing In New York City: Assessing The Differential Impact On NYS Medicaid-Funded Services, Veterans Administration Programs, The Health And Hospitals Corporation, New York State Psychiatric Hospitals, And The New York State Dept. Of Corrections*, Corporation for Supportive Housing, *The New York/New York Agreement Cost Study: The Impact of Supportive Housing on Services Use for Homeless Mentally Ill Individuals*.

sustaining large psychiatric hospitals in urban centers or in rural areas. One of the most straightforward ways to finance community services for individuals who would otherwise be needlessly institutionalized is to redirect institutional funds to community services.

Since 1955, states have been reducing the capacity of their state psychiatric institutions. However, until quite recently they accomplished this by reducing the size of the hospitals, not by closing them down. More recently, states have begun to close entire institutions, freeing up considerable state resources that can be redirected to support community living. For example, more state psychiatric hospitals were closed in the first half of the 1990s than in the 1970s and 1980s combined.⁴² Since 1990, a total of 40 such hospitals have been closed.

Recent experience in Indiana demonstrates how such an approach can produce both positive outcomes for individuals and savings for the state.⁴³ Indiana closed a hospital that was housing individuals with serious mental illness who had a mean length of stay of over eight years. After the hospital closed, most went to some form of 24-hour care or monitoring in the community and were served by programs providing intensive levels of service. The state also provided three years of special funding to local community programs specifically to ease the transition for these individuals. This funding, redirected from hospital spending, allowed communities to meet the needs of discharges without squeezing them into existing treatment slots or adding to already over strained community programs.

The individuals benefitted from services in more integrated settings and showed positive outcomes, such as improved functioning and quality of life. Savings for the state were

⁴² National Association of State Mental Health Program Directors, State Mental Health Agency Profile System Highlights: Closing and Reorganizing State Psychiatric Hospitals: 1996. NASMHPD, Alexandria, VA 1997.

⁴³ McGrew, J. H., Wright, E. R., & Pescosolido, B. A., Closing of a state hospital: An overview and framework for a case study. *Journal of Behavioral Health Services & Research*, 26:3 August 1999, 236-245.

significant. Per-person costs went from \$68,400 for a year's hospital care to \$40,600 for those placed in the community. However, some individuals were placed in alternative institutions (such as nursing homes, which do not represent community integration), whose costs were a little higher. As a result, the overall average cost for the year following closure was \$55,417 per person discharged. Still, this represented a savings of 19 percent of funds expended to maintain these individuals in the state hospital.

Counter to this trend, and to the clear mandate of the Supreme Court's *Olmstead* decision, some states have dug in their heels, and have attempted to rebuild large state institutions, while starving community-based mental health care. One such example is Laguna Honda Hospital, a 1,200-bed skilled nursing facility owned and operated by the City and County of San Francisco. Three fourths of the facility's annual reimbursement comes from Medicaid and Medicare. The city is proposing to build another huge public facility and an assisted living building on the same grounds as the current nursing home. The citizens of San Francisco passed a bond referendum allowing the city to spend up to \$299 million to create a facility or facilities to replace Laguna Honda. Such an expenditure would foreclose the development of the community-care options required under *Olmstead*.⁴⁴

Denial And Inaccessibility of Services

Medicaid is a principal source of funding for the health and mental health services that states offer in the community to public-sector consumers released from institutional settings under the *Olmstead* mandate. The Social Security Act allows states to waive traditional Medicaid rules to set up systems of managed care for Medicaid enrollees. States began using the waivers to offer medical services through managed care. By now, many have expanded their waivers to

⁴⁴ There have also been recent efforts to rebuild state psychiatric hospitals in **Montana and the District of Columbia, two jurisdictions whose community mental health systems have consistently failed adults with mental illnesses.**

include (mental health and addiction treatment for some or all of the Medicaid population.

This shift of Medicaid into managed care arrangements is beginning to blur the borders that have distinguished public and private sectors. At first, the populations with more extensive service needs largely remained in fee-for-service Medicaid programs; however, states are now planning ways to refine these systems to eliminate the inefficiencies of overlapping, cumbersome bureaucracies. They are also beginning to evaluate their expenditures in terms of the clinical outcomes they are purchasing. Whether directly, through managed care contracts with commercial insurance companies, or through states' application of business practices to fee-for-service systems, the experiences of the private market are being transported to the public sector and the respective systems are moving closer together. In communities, individuals and families encounter both considerable overlap and significant gaps in services, with no one organizational structure that can resolve these defects. The trend appears to be increasing with the introduction of managed care plans into Medicaid mental health service delivery.

Community Mental Health is Closed When it Should be Open: As a consequence of underfunding, poor resource allocation and the (not infrequent) desire to shift the cost of hard-to-serve clients to other public systems, the community mental health system in most states is only "open" from 9 a.m. to 5 p.m. Unlike other public systems, like emergency rooms, law enforcement and corrections, which are "open" 24 hours per day, seven days per week, the mental health system is often "closed" (except for hospital-based services) during evenings and weekends, when many people with mental illnesses experience the greatest need. During those times, when adults with mental illnesses come to the attention of the police, they are processed through the justice system (or taken to an emergency room for psychiatric evaluation), rather than being diverted to the less-costly, more appropriate community-based mental health service system that should be meeting their needs.

Geographic Inaccessibility: Even if they have some sort of insurance coverage, many adults with mental illnesses who live in rural areas lack effective access to the mental health services and supports they need because they simply live too far from providers, who are

typically centered in urban and suburban areas. The advent of managed care in the Medicaid and public mental health systems over the past ten years has further diminished the number of providers willing to serve rural clients.

Language and Cultural Barriers: Most state mental health systems still lack the ability to serve people of color and language minorities in their own traditions and their own language. The Surgeon General recently reported “striking disparities” in mental health care for racial and ethnic minorities, and that these disparities “impose a greater disability burden on minorities,” and that people from diverse cultures collectively experience a greater disability burden from mental illness than do whites. This burden is directly attributable to the fact that people from diverse cultures systemically receive less care and poorer quality of care, rather than from their illnesses being inherently more severe or prevalent in the community.⁴⁵

TRAGIC CONSEQUENCES FOR ADULTS AND FOR SOCIETY

Homelessness: On any given day, approximately 150,000 people with severe mental illnesses are homeless, living on the streets or in public shelters. Homelessness is not a symptom of mental illness. It is an artifact of mental health systems that do not link consumers to accessible housing and do not offer needed supports and services, or that operate residential programs experienced by consumers of mental health care as coercive. Homelessness among people with serious mental illnesses underlies many of the problems that spill over from the mental health system, including the problem of criminalization. Yet the successes reported by many local programs demonstrate that most homeless people with mental illnesses can live with stability in their communities if they receive a combination of sustained outreach, case management, health and mental health services, housing and employment assistance.⁴⁶

⁴⁵ *Mental Health: Culture, Race, and Ethnicity: A Supplement to Mental Health: A Report of the Surgeon General*, available at <http://www.surgeongeneral.gov/library/mentalhealth/cre/default.asp>

⁴⁶ National Coalition for the Homeless and National Law Center on Homelessness

Criminalization of Mental Illnesses: Jails are becoming America's new mental hospitals. As a result, jail facilities are faced with a role they were neither designed nor staffed to assume. Between 600,000 and one million men and women jailed each year have a mental illness. This is thought to be eight times the number admitted to psychiatric hospitals. Many of these people are arrested for non-violent misdemeanors, others for "crimes of survival" such as stealing food, loitering, or trespassing. Still others are detained in "mercy arrests" by police officers who find the public mental health system unresponsive and the process of accessing its emergency services cumbersome.

As many as 16 percent of all jail inmates have a severe mental illness, according to the U.S. Department of Justice. Many were arrested for reasons related to their unmet needs for mental health or addiction treatment and for housing. Many people with mental illnesses are homeless and frequently arrested for "esthetic" or "quality of life" misdemeanors that result from their lack of access to mental health services and that police routinely ignore when committed by others.

Predominantly, prisoners with mental disabilities are poor and people of color. Along with details about the plight of other major racial and ethnic minority groups, a report released August 26, 2001, by the U.S. Surgeon General, entitled *Mental Health: Culture, Race and Ethnicity*, indicates that disproportionate numbers of African Americans are represented in the most vulnerable segments of the population—people who are homeless, incarcerated, in the child welfare system, victims of trauma—all populations with increased risks for mental disabilities.

People with mental illnesses, with mental retardation, and with associated substance abuse (hereinafter "people with mental disabilities") are increasingly brought into the criminal justice system. They are arrested for various minor offenses—many times for "crimes of survival" as they struggle to live on the streets—and incarcerated in jails and prisons where their

and Poverty, *Illegal to be Homeless: The Criminalization of Homelessness in the United States* (January 2002).

treatment needs are not met. Typically, these are offenses people who do not have mental disabilities either would not commit or which prompt a warning...not an arrest. Often, people with mental disabilities are living in circumstances so characterized by neglect that police and others in the community may even view these arrests as acts of "mercy."

Instead of punitive actions, these individuals need assistance. However, failures in service systems and the lack of collaboration between mental health, mental retardation, substance abuse, and criminal justice systems prevent them from receiving adequate supports and care. This is especially true for individuals who are homeless, whose mental illness is particularly hard to treat, and those with co-occurring substance abuse.

In addition to being greater in number, inmates with mental illnesses tend to have a history of more significant problems when compared with other inmates. Many lead chaotic lives. Inmates with a mental illness were less likely to be employed in the month before the arrest; 37.7 percent in federal prisons were unemployed, compared with 27.5 percent of inmates who did not have a diagnosis of mental illness. Inmates with a mental illness are more likely to reflect one or more of the factors that put people at risk, such as:

- growing up in foster care;
- living with a substance-abusing parent;
- or being physically or sexually abused;
- More likely to have been homeless;
- More likely to be unemployed at the time of arrest;⁴⁷

⁴⁷ Ditton, P.M. (1999). Mental health and treatment of inmates and probationers (Bureau of Justice Statistics, NCJ-174463, p.5). Washington, DC: U.S. Department of Justice.

- More likely to be under the influence of drugs or alcohol at the time of the arrest;⁴⁸
- More likely to grow up in foster care, agency or institution;⁴⁹
- More likely to have been physically or sexually abused while growing up;⁵⁰ and/or
- More likely to grow up with a parent who abused alcohol.⁵¹

Once incarcerated, these men and women are even less likely to receive adequate treatment than when they were at liberty—both because the criminal justice system lacks the capacity to deliver comprehensive mental health services and because punitive jail settings are the antithesis of a therapeutic environment. In all likelihood, the number of incarcerated people with disabilities has increased, given the extensive publicity accorded to violent acts by people with mental illnesses, however rare, along with the increased public cynicism about deinstitutionalization, the diminished tolerance of abnormal behavior and the expanding use of police tactics such as “mercy arrests.”⁵²

⁴⁸ Id. at 7.

⁴⁹ Id. at 6.

⁵⁰ Id.

⁵¹ Id.

⁵² Inmates with mental illnesses tend to have a history of more significant problems when compared with other inmates. Many lead chaotic lives. The DOJ report found that: More than three quarters of inmates with a mental illness had at least one prior prison, jail or probation term; twenty percent of inmates were homeless in the 12 months prior to arrest, compared to 8.8 percent of other inmates; inmates with a mental illness were less likely to be employed in the month before the arrest; 37.7 percent in federal prisons were unemployed, compared with 27.5 percent of inmates who did not have a diagnosis of mental illness; and inmates with a mental

While some jails and prisons provide mental health services, the emphasis should not be on improving these services in a coercive anti-therapeutic environment. Rather, investment should be made in diversion. It should extricate people with mental illnesses from the revolving door of re-arrest, they must be provided with discharge planning to help them obtain public benefits and link them to community treatment. Yet nationally, only one third of inmates with mental illnesses receive discharge planning services.

When released from jail or prison, inmates with mental illnesses seldom receive the assistance they need for successful re-entry into the community.⁵³ Without adequate discharge planning prior to release, they have no access to medication and other needed mental health services, to housing, or to employment or income support.⁵⁴ Studies have shown that recidivism rates fall when discharge planning and linkage to effective aftercare services is provided.

illness are more likely to reflect one or more of the factors that put people at risk, such as growing up in foster care, living with a substance-abusing parent, or being physically or sexually abused.

⁵³ Until litigation was commenced against it, New York City fought the obligation to provide discharge planning in court (*Brad H. v. City of New York*). The city would drop inmates released from Rikers Island at a toll plaza in the middle of the night with \$1.50 and two subway tokens. People who took medication while incarcerated are released without a supply to carry them until they can obtain and fill a prescription. No one ensures that they have access to public benefits such as SSI and Medicaid, which they could use to obtain housing and mental health treatment. Currently, however, the city has adopted a special program where inmates diagnosed with mental illnesses who are discharged from jail can have their medications subsidized until they are able to re-establish Medicaid benefits.

⁵⁴ A 1997 study revealed that only 20 percent of jails nationwide engage in discharge planning. This means that most former inmates with serious mental illnesses enter a void when they walk out of the correctional facility. It is no wonder that the recidivism rate among people with mental illnesses is extremely high. An effective discharge plan is crucial to the successful re-entry into the community of an inmate with a serious mental illness. Case managers who initiate the appropriate process prior to the inmate's release must also be able to follow up afterwards to make sure the individual has in fact received benefits and services.

Individuals sentenced to jail or prison lose their entitlement to Medicaid and other public benefits. There is even a financial incentive for correctional institutions that promptly report prisoners' intake to the Federal Government. But there is no incentive to the criminal justice system to help released prisoners reestablish or initiate such benefits. Reinstatement involves complex paperwork and applications take months to process—months during which many former inmates have no money for medication or housing, much less counseling.

As is the case with discharge from psychiatric hospitals, the incidence of recidivism among people with mental illnesses is directly related to the quality of post-discharge treatment and supports, including housing. The comprehensive support model pioneered for homeless people by CSH is highly appropriate for people with mental illnesses who are returning to the community from jails and prisons.

Rather than focus on the handful of far-from-typical violent criminals with *untreated* mental illness public policy should concentrate on diverting non-violent offenders with serious mental illness from the criminal justice system into community-based treatment programs and expanding those programs so as to reduce recidivism and prevent the actions that prompt arrest. While those who have committed serious offenses should receive mental health treatment in jail, for those who have committed only minor offenses that are the result of or associated with their illness, incarceration is neither cost effective, humane nor just. By definition, a penal institution constitutes a non-therapeutic environment. In fact, inmates with mental illness are at risk of being victimized, sexually abused and at increased risk of suicide. (Ninety-five percent of prison or jail suicides involve inmates with a diagnosed mental illness.)

The problem of criminalization of people with mental illness has been exacerbated by the failure of mental health systems to meet the needs of people in the community after deinstitutionalization vastly reduced the population in state psychiatric hospitals. The vision of deinstitutionalization was to allow individuals with mental illness to be full participants in the community. This goal is even more realistic today than it was in the 1960s. New anti-psychotic

medications, effective community services (even for those with the most serious disabilities), and new breakthroughs in treating co-occurring mental illness and substance abuse, make successful community living a real possibility for the vast majority of people with mental illness. To succeed, however, they need access to an array of comprehensive services, from housing to intensive community mental health services.

Although preventing incarceration must always be the goal, there will also be a continuing need for policies and programs that can provide more effective solutions when people with mental illness make contact with the criminal justice system. There have been isolated attempts to address this problem through the use of diversion programs, using the criminal justice process to steer people with mental illness from jail and into mental health treatment.

Diversion programs offer a variety of approaches, some of which have been criticized for offering no more than a choice “between forced medication or jail.” Although diversion programs have been determined effective from a criminal justice perspective—i.e., their use reduces the number of inmates with mental illness—their efficacy has not been studied from a mental health or civil rights perspective. We need to know whether people with mental illness who are diverted from jails are receiving mental health treatment that allows them to participate in community life and avoid further contact with the criminal justice system and whether their civil rights have been respected during the process.

Mental Health Courts

As a response to the growing number of people with mental illnesses being confined to jail or prison, a number of local jurisdictions have developed mental health courts. These specialty courts are modeled on drug courts, and purport to focus on “therapeutic jurisprudence” rather than punishment. In 2000, Congress passed legislation to provide limited funding for mental health courts in 50 jurisdictions.

Advocates, however, are wary of the courts:

Mental health courts are, to many people, an appealing response to criminalization. But the mental health courts that exist so far, with very few exceptions, accept only people charged with non-violent low-level offenses. While these courts help some people get services, they do nothing to help mental health consumers facing prison or lengthy jail sentences, and they do not reduce criminalization. If mental health courts increase the “price” of minor offenses, as some undoubtedly do, their effect is actually to expand criminalization, a phenomenon known as “net-widening.”⁵⁵

This “net-widening” is of concern because police officers may arrest people whom they would have otherwise warned, told to “move on”, or ignored in an effort to secure them services via the mental health court. Mental health courts may also result in people with mental illness receiving more severe sanctions for petty criminal offenses than they would have received through the regular court system. They may spend more time in jail or other secure confinement; they may find themselves under judicial supervision for a longer period of time, and they may have to plead guilty to charges that might otherwise have been dismissed. Moreover, they may not be adequately counseled by their lawyers as to these potential risks, and judges and court personnel may be giving inaccurate information concerning these risks.

Poverty/Unemployment: Improvements in treatment and advances in community-based rehabilitation services mean that more people with serious mental illnesses are able to work.

Unfortunately, the unemployment rate for people with mental illness hovers at 85 percent, higher than for any other disability group. Factors such as stigma and public misperception of mental illnesses only partially account for this situation. Many people can and do recover from mental illness. A variety of specialized services such as supported employment, transitional employment and psychosocial rehabilitation enable people with mental disabilities to work and have a satisfying and rewarding career.

⁵⁵ Heather Barr, *Mental Health Courts: An Advocate's Perspective*, available at the “Mental Health” tab, at <http://www.urbanjustice.org/publications/index.html>.

Several federal agencies provide vocational rehabilitation services for people with disabilities: the state-federal public vocational rehabilitation system, the Social Security Administration and the Department of Labor. These federal programs work cooperatively with state and private rehabilitation providers to increase employment among people with disabilities. Recent federal legislation includes provisions to facilitate work for those who receive disability benefits by allowing easy re-entry into rehabilitation programs if there is a reoccurrence of symptoms and by creating a voucher program to allow consumers to go to the provider of their choice.

The federal Vocational Rehabilitation (VR) program provides funds to states for assisting individuals with disabilities to work. Unfortunately, state VR programs focus primarily on individuals with less serious disabilities. People with severe mental illnesses, in particular, do not fare well in these systems, because they frequently require intensive services over longer periods of time to obtain and maintain employment.

Moreover, considerable VR resources are spent on eligibility-determinations and administrative functions, while inadequate resources go to direct services. Months or even years may pass between the time an individual with a severe mental illness applies for VR services and the time that services actually begin.

While the recently enacted Ticket to Work and Work Incentives Improvement Act of 1999 theoretically enhances the ability of a person with a psychiatric disability to find work without losing income and Medicaid benefits, the new law is very complicated, and has not led to significant new job opportunities.

Involuntary Outpatient Commitment

In many states, the abject neglect of the needs of people with psychiatric disabilities and the predictable deterioration that will be experienced by some has led to a call for more coercive practices, like involuntary outpatient commitment (IOC). IOC is a legal strategy that utilizes

court orders and other means to force individuals with psychiatric disabilities to participate in mandatory treatment, merely because someone else has made a judgement that they would benefit from psychiatric treatment. An individual can be forced into treatment despite the fact that no crime has been committed and notwithstanding that he/she does not meet the requirements for inpatient commitment (i.e., that the person is a clear and present danger to self and/or others).

When a court issues a civil commitment order, requiring an individual to submit involuntarily to treatment for a serious mental illness, the person has historically been confined to inpatient treatment in a public hospital. Today **there is new interest in IOC, linked to media reports of violent acts by individuals with diagnoses of serious mental illnesses and, according to state advocates and mental health consumers, fueled by a sophisticated public relations campaign by the Treatment Advocacy Center. Increasingly, the providers of mental health services to individuals thus committed are private-sector programs, including psychiatric clinics and group homes.**

Private providers—whose cooperation is required to implement these statutes—are split on IOC. A good many, particularly social workers, case workers and others working on a person-to-person level, believe that the requisite reporting on their clients harms the therapeutic relationship and that the clients’—not coerced,—but voluntary participation is essential to the healing process.

The National Council on Disability has previously expressed its concerns about such coercion, and reiterates them here:

Mental health treatment should be about healing, not punishment. Accordingly, the use of aversive treatments, including physical and chemical restraints, seclusion, and similar techniques that restrict freedom of movement, should be banned. Also, public policy should move toward the elimination of electro-convulsive therapy and psycho surgery as unproven and inherently inhumane procedures. Effective humane alternatives to these techniques exist now and should be

promoted.⁵⁶

Involuntary outpatient commitment is a very costly effort to the individual, to the mental health system, to the criminal justice system, and to society that holds no promise of the avoidance of violence in our society, nor of recovery for the individual. It diverts badly needed funding away from effective community-based mental health services, especially those founded upon the recovery vision.

Like so-called "mercy arrests" that bring people with mental illnesses into the criminal justice/correctional system, IOC is used far too often to compensate for gaps in community services that would otherwise engage mental health consumers on a voluntary basis.

Psychiatric Hospitalization

When all else fails, the mental health system retains the ability to petition for the involuntary civil commitment of a person whose mental illness makes him or her a threat to self or others. In the civil commitment context, federal courts have said that the Due Process Clause requires a balancing of the individual's interest in liberty against the state's interest in providing care and treatment to the individual in order to protect the public (police power) or to protect the individual (*parens patriae*).⁵⁷

As outlined above, however, the crisis focus of mental health services virtually ensures

⁵⁶ National Council on Disability, *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* (January 20, 2000).

⁵⁷ *Vitek v. Jones*, 445 U.S. 480, 491-492 (1980) ("We have recognized that for the ordinary citizen, commitment to a mental hospital produces a massive curtailment of liberty."); *Addington v. Texas*, 441 U.S. 418, 425, 99 S.Ct. 1804, 1809, 60 L.Ed.2d 323 (1979) (because of the consequences, a person with mental illness cannot be committed without due process of law).

that "all else" *will* fail, and the system will have to rely upon hospitalization.

Chapter 5

Impact on Seniors

Crisis Focus

Like younger adults, seniors with psychiatric disabilities and limited incomes rely upon public mental health services and supports they may need to live successfully in the community. They rely upon many of the same providers as do younger adults, although the possibility of physical disabilities or frailty in this population make it more likely that they may be living in nursing homes, assisted living facilities or other similar settings that may not adequately provide mental health services and supports. In those instances, many seniors either go entirely without such services, accept the marginal services that may be available in those settings, or depend upon the limited services and supports funded by Medicare or Medicaid and delivered by community-based providers.⁵⁸

Mental health care for older Americans is no better than for the younger cohorts considered in earlier chapters. According to the American Association of Geriatric Psychiatry, nursing homes currently are charged each year with the care of 1.5 million older Americans. More than half suffer from some sort of cognitive impairment and as many as 80 percent have a diagnosable psychiatric disorder. Despite the high prevalence of people with mental disabilities in nursing homes, according to the Surgeon General's report, "these settings generally are ill

⁵⁸ Mental health spending in Medicare, Medicaid and other federal programs has grown more slowly than overall program spending. *Mental Health: A Report of the Surgeon General*, 1999, p. 417. Medicare law also limits the program's effectiveness in meeting the needs of enrollees with mental and emotional disabilities. Medicare requires beneficiaries to pay 50 percent of the cost of outpatient mental health treatment, but only 20 percent of other outpatient services. Medicare also provides no coverage for services that are critical for individuals with serious mental illness (case management, psychiatric rehabilitation and medication) and imposes a discriminatory lifetime limit of 190 days on coverage for care in a psychiatric hospital.

equipped to meet their needs.”⁵⁹

Likewise, in the *Journal of General Psychiatry*, mental health experts from around the country warn that “(a) national crisis in geriatric mental health care is emerging. The present research infrastructure, healthcare financing, pool of mental health care personnel with appropriate geriatric training, and the mental health care delivery system are extremely inadequate to meet the challenges posed by the expected increase in the number of elderly with mental illness as well as an anticipated increase in late-onset mental illness as more people live longer.”

Significant challenges to the mental health of older adults relate less to our clinical capacities than they do to older adults not having access to services known to be effective. For example, notwithstanding the high prevalence of depression among older adults, the Surgeon General reports that only 11 percent of older adults are receiving adequate treatment and 55 percent receive no treatment whatsoever. Indeed, very few of the 15-25 percent of older adults over 65 who—according to U.S. Census Bureau estimates—have a mental illness, receive treatment. Most community surveys suggest that 1 percent or fewer older adults in their community receive psychiatric care. They remain underserved by mental health providers, as shown by the following data:

- Only 4 percent of community mental health center patients are over 65.
- Fewer than 4 percent of the patients seen by private practitioners are older adults.
- Less than 1.5 percent of all community-based mental health care goes to older adults.

A number of factors contribute to the lack of community-based services for older adults with mental illnesses. Many elders in nursing homes whose chronic physical ailments do not

⁵⁹ Lombardo, N. E. (1994). Barriers to mental health services for nursing home residents. Washington, DC: American Association of Retired Persons Policy Institute.

require institutionalization (e.g., diabetes) are confined to these settings because they have a serious mental illness—although effective treatment for both the former and the latter is routinely administered in the community.

Additionally, to a degree, the low utilization rates for community-based care reflect older cohorts' sense of shame around mental health problems and their aversion to seeking help. But they also are testimony to stagnant public systems that have long traditions of neglecting older adults' mental health needs that afford older adults low priority and that, rather than providing rehabilitation, relegate older adults to custodial care services. The consequences of the unavailability or inaccessibility of appropriate services to older adults with mental illness include additional and unnecessary disability, needless dependency and vulnerability to institutional segregation.

Missed Opportunities for Prevention

Older adults are the most rapidly growing segment of our population. Due in part to increasing life expectancy, people over 65 are expected to grow in number from 20 million in 1970 to 69.4 million by 2030, outnumbering people between 30 and 44. Additionally, there is evidence that the number of older adults with mental illness will also increase in terms of both numbers and in the percentage of the total population that those numbers represent. Thus, the number of older adults with mental illness is projected to swell from about four million in 1970 to 15 million in 2030.

Denial and Inaccessibility of Services

The December 1999 *Report of the U.S. Surgeon General*—the first of 51 such reports to focus on mental health—devotes a chapter specifically to older adults and mental health. While acknowledging the capacity for sound mental health among older adults, the report notes “a substantial proportion of the population 55 and older—almost 20 percent of this age group—experience specific mental disabilities that are not part of normal aging. Unrecognized or

untreated, depression, Alzheimer's disease, alcohol and drug misuse and abuse, anxiety, late-life schizophrenia and other conditions can be severely impairing, even fatal; in the United States, the rate of suicide, which is frequently a consequence of depression, is highest among older adults relative to all other age groups (Hoyer et al., 1999)."

Yet there are effective interventions for most mental disabilities experienced by older persons (for example, depression and anxiety and many mental health problems such as bereavement). Further, the Surgeon General's report asserts that "treating older adults with mental health disorders accrues other benefits to overall health by improving the interest and ability of individuals to care for themselves and follow their primary care provider's directions and advice, particularly about taking medications."

The Supreme Court's *Olmstead* decision has particular significance for older adults with mental disabilities. Arguably—more so than any other group with mental illness—older adults have endured a long history of flagrant segregation and societal neglect, most graphically demonstrated in the deplorable "geriatric back wards" of state psychiatric hospitals. Despite the shift away from psychiatric institutions and the promise of community mental health services, older adults continue to be afforded "back ward" status, as evidenced by a paucity of community-based mental health services, limited opportunities for integrated housing, and service systems that emphasize custodial care over rehabilitation. In fact, largely motivated by cost savings and convenience rather than clinical need, substantial numbers of older adults with mental disabilities were trans-institutionalized from state psychiatric hospitals to nursing homes. Among other people with mental disabilities, the pivotal *Olmstead* decision applies to:

- long-stay patients in psychiatric hospitals who do not need to be there;
- individuals who frequently cycle in and out of hospitals as a result of a lack of community services;
- residents in nursing homes who can appropriately be served in the community;

- individuals residing in the community, but at risk of institutionalization unless they receive appropriate care.

Like younger people with mental illnesses, seniors are at significant risk of unnecessary institutionalization. A recent analysis of *Olmstead* complaints filed with the Office of Civil Rights of the U.S. Department of Health and Human Services reveals that 60 per cent of the complaints have been filed by people living in nursing homes.⁶⁰ ADA—and the integration mandate, in particular—compels states to consider the civil rights of people with disabilities and to determine whether their systems of care perpetuate needless segregation and its harmful effects. As states move to comply with these legal requirements for diverse populations of disabled individuals, aging advocates face the challenge of ensuring that older adults are not put at the end of the line as they compete for limited resources.

⁶⁰ Center for Health Care Strategies, *An Analysis of Olmstead Complaints: Implications for Policy and Long-Term Planning* (2001), available at <http://www.chcs.org/publications/pdf/cas/olmsteadcomplaints.pdf>. The report does not distinguish between seniors and younger adults living in nursing homes.

Chapter 6

Fulfilling the Promise: Concrete Steps Toward a New Vision

For each population covered in this report, there are concrete steps that can be taken to improve the quality and effectiveness of mental health services and supports.

Children and Youth

ENABLING CHILDREN AND YOUTH WITH MENTAL OR EMOTIONAL

DISABILITIES TO FLOURISH IN THEIR COMMUNITIES: Children with emotional disabilities fall through an historic gap between the various child-serving agencies in the public sector—notably, the education, child welfare, juvenile justice and mental health systems. Efforts to improve this situation should focus on promoting the systems of care that have been demonstrated effective in bridging the gap and enabling children to receive Medicaid-funded wraparound services in their homes or in residential settings near their families.

STATE EFFORTS TO EXPAND MEDICAID COVERAGE TO CHILDREN AND YOUTH WITH EMOTIONAL DISTURBANCE THROUGH THE USE OF WAIVERS

AND OPTIONS. Since Congress has recently provided states with an opportunity—through the Child Health Insurance Program—to expand Medicaid coverage to families with incomes higher than the Medicaid eligibility ceiling, the Medicaid entitlement can likewise be extended to more children. Studies of home-and community-based waivers have focused primarily on the growth in the number of waivers and the cost-effectiveness for aged individuals, individuals with mental retardation and developmental disabilities and persons with AIDS. Among the groups covered in the mid-1990s, individuals with mental retardation and developmental disabilities reflected the most rapid growth. They increased from 74,000 in 1992 to 146,000 in 1996. The Centers for Medicare and Medicaid services is currently funding a study to evaluate the impact on quality of life, quality of care, utilization, and cost for individuals with mental retardation and developmental disabilities. Few studies have examined the use of home-and community-based

waivers for children with emotional disturbance.

PREVENTING EXCLUSION FROM SCHOOL OF CHILDREN WITH EMOTIONAL

DISTURBANCE: Identify and disseminate a range of services that progressive school systems have provided through IDEA and under court and administrative rulings, identifying for state policymakers and advocates the maximum range of community-based services for children with emotional disturbance that can be furnished under the IDEA, and enforce the requirement to conduct functional behavioral assessments and to provide positive behavioral supports.

PREVENTING CUSTODY RELINQUISHMENT THROUGH ACCESS TO CHILD

MENTAL HEALTH SERVICES: The Family Opportunity Act would create a new state option to allow states to expand Medicaid coverage to children with disabilities up to age 18, who would be eligible for SSI disability benefits except for family income or resources. Any family with a child whose disability meets SSI criteria and whose income does not exceed 300 percent of the poverty level could be covered under Medicaid if the state chooses this option. The bill also creates a time limited demonstration program to extend Medicaid coverage to children who have a disability that would become severe enough to qualify under SSI if they are left to deteriorate without health care. The demonstration will provide useful information on the cost effectiveness of early health care intervention for children with potentially severe disabilities.

The Family Opportunity Act would add residential treatment centers to the waiver statute and thus allow states to provide waivers to families seeking home and community based services instead of more restrictive care in such centers.⁶¹

⁶¹The bill adds the words "inpatient psychiatric hospital services for individuals under 21" to the waiver language. This phrase is defined in the Medicaid statute to include any facilities that the Secretary of HHS includes in regulations. HHS has promulgated a regulation which includes residential treatment facilities as inpatient psychiatric services for individuals under 21, if the facilities meet certain criteria.

EXTENDING MEDICAID AND OTHER BENEFITS TO YOUTH AGING OUT OF

FOSTER CARE: The vast majority of young people in the foster care system are there because they have experienced some form of childhood maltreatment. Research reveals that negative childhood experiences, especially abuse and neglect, can adversely affect adult health and mental health. Adults with aversive childhood experiences are also more likely to be depressed, attempt suicide, have unintended pregnancies, and have personality disorders. Substance abuse problems and alcoholism are also correlated with negative childhood experiences. Extension of Medicaid benefits will help address the needs of these youths. Health care benefits will allow young people to receive treatment for health or mental health problems before the problems become severe.

FEDERAL LEGISLATION ON AMENDING INSURANCE LAWS TO END PRACTICES THAT HAVE THE EFFECT OF DISCRIMINATING AGAINST PERSONS WITH MENTAL ILLNESS: Legislation should be drafted to address the unequal access to mental health care that is prevalent in all aspects of the United States health care system, including private insurance, public insurance, and programs designed to bridge the gaps between the private and public health insurance sectors.

DOCUMENT HOW EXISTING ENTITLEMENT PROGRAMS CAN BE USED TO PREVENT CONTACT WITH THE JUVENILE JUSTICE SYSTEM AND TO DIVERT CHILDREN AND YOUTH FROM JUVENILE JUSTICE. In its 2000 report, *From Privileges to Rights*, NCD called upon Federal, state, and local governments, including education, health care, social services, juvenile justice, and civil rights enforcement agencies to work together to reduce the placement of children and young adults with disabilities, particularly those labeled with emotional disturbance, in correctional facilities and other segregated settings. These placements are often harmful, inconsistent with the federally-protected right to a free and appropriate public education, and unnecessary if timely, coordinated, family-centered supports and services are made available in mainstream settings.

Advocates have begun to document how existing entitlements to family supports and community-based intensive mental health treatment can prevent children's behavior from

deteriorating to the point of warranting incarceration. The National Mental Health Association and the GAINS Center have recommended that communities: (1) formalize screening and assessment for mental health and substance abuse for youth at all points of contact of the juvenile justice system; (2) provide the full range of mental health and substance abuse services and supports to youth, and cease the piece meal, stop gap approach that currently exists; and (3) establish a coordinating body or task force that focuses on this population of youth.⁶²

PROTECTING BENEFITS UNDER WELFARE REFORM FOR PARENTS WITH MENTAL ILLNESSES AND PARENTS WHOSE CHILDREN HAVE EMOTIONAL

DISABILITIES: As Congress considers reauthorization of the 1996 "welfare reform" law, it has the opportunity to strengthen the entitlement to cash payments and Medicaid benefits for poor families in which a parent or child has significant mental health issues which prevent a head of household from returning to work.

Adults and Seniors

ADA/OLMSTEAD OFFER SOLUTIONS: ENDING ISOLATION AND SEGREGATION

While a state is not obliged to assume an "undue burden" in its pursuit of integrated services for people with serious mental illnesses, nothing in *Olmstead* requires community placements to be "cost-neutral." Indeed, the entire tenor of the decision is to the contrary. The court recognizes that needless institutionalization is a wrong that the ADA was designed to redress. It is clear that an accommodation under the ADA can be reasonable even if it imposes costs.

The court did not identify when it would be "too costly" for a state to provide services in the community. (The issue was not before the court.) Instead, the court identified relevant factors, the most significant being the resources available to the state to fund community

⁶² National Mental Health Association and GAINS Center, *Justice For Juveniles: How Communities Respond To Mental Health And Substance Abuse Needs Of Youth In The Juvenile Justice System*. Executive summary available at <http://www.nmha.org/children/justjuv/execsum.cfm>

services. While the existing community services system constitutes one available resource, the court made clear that other resources must also be counted. The *Olmstead* decision anticipates the reallocation of resources to fund community placements.

In evaluating what resources are available to finance community placements, states need to look both at services that are currently funded and at how community services might be funded if the state took action to maximize its budget. These "available resources" can include resources that the state could obtain by aggressively seeking additional funds—from the legislature, by restructuring its Medicaid program or through similar strategies.

PROVIDE A LEGALLY ENFORCEABLE RIGHT TO MENTAL HEALTH SERVICES

AND SUPPORTS: By providing a right to services and supports "in sufficient amount, duration, scope and quality to support recovery, community integration and economic self-sufficiency," a law could transcend the age-old debate about inadequate funding.

For example, the Bazelon Center for Mental Health Law has drafted a proposal which would provide a legally enforceable right to recovery-oriented mental health services and supports, and will be working with advocates in several states around the country to press for its adoption.⁶³ This proposal seeks to reshape the debate about mental health system reform. This initiative is driven by a growing consensus among many stakeholders that traces a host of social ills affecting adults with serious mental illnesses—homelessness, vagrancy, criminalization and so-called "mercy arrests", unemployment and needless dependency on public systems—to a single cause. That cause is the inadequacy of the public mental health system, which does little more than provide crisis services and fails to meaningfully address the long-term rehabilitative needs of the population it serves. It is clear that the absence of an entitlement to appropriate, timely mental health services has increased the number of people with mental illnesses in crisis.

⁶³ Bazelon Center for Mental Health Law, *A New Vision of Public Mental Health: A Model Law to Provide a Right to Mental Health Services and Supports*, available at <http://www.bazelon.org/newvisionofpublichealth.html>.

MAXIMIZE THE AVAILABILITY OF MENTAL HEALTH SERVICES AND SUPPORTS PROVIDED THROUGH CONSUMER-DIRECTED ORGANIZATIONS:

People labeled with psychiatric disabilities should have a major role in the direction and control of programs and services designed for their benefit. This central role must be played by people labeled with psychiatric disabilities themselves, and should not be confused with the roles that family members, professional advocates, and others often play when "consumer" input is sought. For the past decade, the Federal Government has provided funding and logistical support for three consumer-run technical assistance centers. These centers have helped to document, establish and refine successful alternative approaches to the provision of mental health services and supports through the use of other people who have experienced mental illnesses. The Federal Government should increase incentives to state mental health systems to adopt such models and to expand their use.

ENSURE THAT ALL MENTAL HEALTH SERVICES AND SUPPORTS ARE VOLUNTARY IN NATURE, AND NOT CONTINGENT ON COMPLIANCE WITH MEDICATION OR TREATMENT PLANS:

NCD reaffirms its commitment to the principles enunciated in its 2000 report, *From Privileges to Rights*: "Eligibility for services in the community should never be contingent on participation in treatment programs. People labeled with psychiatric disabilities should be able to select from a menu of independently available services and programs, including mental health services, housing, vocational training, and job placement, and should be free to reject any service or program. Moreover, in part in response to the Supreme Court's decision in *Olmstead v. L. C.*, state and federal governments should work with people labeled with psychiatric disabilities and others receiving publicly-funded care in institutions to expand culturally appropriate home- and community-based supports so that people are able to leave institutional care and, if they choose, access an effective, flexible, consumer/survivor-driven system of supports and services in the community."

FEDERAL LEGISLATION ON AMENDING INSURANCE LAWS TO END PRACTICES THAT HAVE THE EFFECT OF DISCRIMINATING AGAINST PERSONS WITH MENTAL ILLNESS:

Legislation should be enacted to address the unequal access to

mental health care that is prevalent in all aspects of the United States health care system, including private insurance, public insurance, and programs designed to bridge the gaps between the private and public health insurance sectors.

A longstanding history of discrimination and recrimination has led to policies which systemically deny needed health care to millions of Americans with severe mental health needs. People with mental illness have been alternatively thought of as possessed by evil spirits, lazy, responsible for their own illness, and infantile. In the past, individuals with mental health impairments were locked in institutions. Today, they are locked in jails and prisons because they are unable to access the care that they need.

The underlying stigma surrounding mental illness has led to systemic inequality in all health care delivery. For example, the private sector refuses to insure individuals with a history of any mental health treatment, when they will insure an individual with more severe physical health care needs. In addition, caps on doctors' visits, hospital days and other services are placed on mental health care, but not on physical health care.

Private insurance, however, is evenhanded between physical and mental health care in its denial of long term care to individuals with ongoing health care needs. To address this gap in private coverage, the Medicaid program has developed waivers and options which provide health care coverage for a more intensive package of services to individuals who would not usually qualify for publicly funded health care by virtue of their income. These "bridge" programs, however, do not meet the needs of individuals with mental health impairments. For example, the waiver and option statutory language does not include residential treatment facilities, which are where most children with serious emotional disturbance languish for long periods. As a result, only 3 states have received waivers for children with serious emotional disturbance, where 50 states have waivers for children with developmental disabilities. In addition, almost half the states with an option program for children do not serve any children with a primary diagnosis of serious emotional disturbance. States fail to serve children with mental health needs even though the federal statutory language does not exclude them in any way and makes the option available

to any child with a disability.

Finally, Medicare and Medicaid, the public health safety net, provide unequal services to individuals with mental health needs. Medicare reimburses a much lower percentage of mental health care costs than physical health care costs. Medicaid also fails to meet the needs of individuals with mental illness. States do not include needed mental health services in their Medicaid plans. When individuals enter jails and prisons because of a lack of services in the community, their Medicaid coverage is immediately terminated in every state, despite federal law which allows states to suspend coverage and thus, facilitate reentry into the community upon discharge. Under the Early Periodic Screening Diagnosis and Treatment program mandating necessary services for children, few states provide an adequate mental health screening tool for children and studies indicate that large percentages of children are not screened at all. Federal law does not require states to report on mental health screening rates or ensure that an adequate mental health screening tool is used.

All three means of health care coverage—public, private and bridge programs—create barriers to the receipt of mental health care. These barriers have led to the current national crisis, with individuals with severe mental health needs increasingly relying on emergency room care, prisons, and jails to fill the gap. Congress must act to remove those impediments and redress the longstanding discrimination against individuals with mental illness which can only be explained by ignorance and stigma.

NCD reiterates the concern expressed in *From Privileges to Rights* that to assure that parity laws do not make it easier to force people into accepting "treatments" they do not want, it is critical that these laws define parity only in terms of voluntary treatments and services.

IMPROVE VOCATIONAL REHABILITATION (VR) SERVICES: Individuals with severe mental illnesses would like the option to seek VR services directly from private programs with proven track records in providing effective services, bypassing ineffective, VR bureaucracies. A variety of approaches could be considered, such as providing vouchers that would permit

individuals to purchase services from a range of programs meeting quality standards.

The Ticket to Work and Work Incentives Improvement Act is a step in this direction because it authorizes the Social Security Administration to provide vouchers that allow consumers on SSI and SSDI to select their own training and placement provider. The ticket pays private providers over a 60-month period, so long as the individual stays off cash benefits, thereby creating strong incentives for providers to offer ongoing, flexible supports and services designed to keep individuals in jobs. However, to benefit from this program individuals must have been receiving federal disability benefits and must be able to work full time. Other individuals with disabilities could also benefit from psychiatric rehabilitation services, yet there is no program for them under the Rehabilitation Act.

ESTABLISHING A RIGHT TO MENTAL HEALTH DISCHARGE PLANNING PRIOR TO RELEASE FROM JAIL OR PRISON

A national strategy is needed to stop the revolving door for inmates with mental illnesses. Establishing a right to discharge planning under federal law would have a far greater impact than a series of state decisions, however valuable. Establishing a right to discharge planning is only one step toward ending the harmful, often cyclic, incarceration of people with mental illnesses.

Efforts are also underway to reconnect former inmates with federal benefit programs like Supplemental Security Income and Medicaid, so that they have some income, health care and medication benefits to help them transition successfully back to the community.⁶⁴

PROVIDE ADEQUATE FUNDING FOR ENFORCEMENT OF THE ADA, IDEA, FAIR HOUSING ACT AND OTHER CIVIL RIGHTS LAWS AFFECTING PEOPLE WITH

⁶⁴ See Bazelon Center for Mental Health Law, *Finding the Key to Successful Transition from Jail to the Community: An Explanation of Federal Medicaid and Disability Program Rules* (2001).

PSYCHIATRIC DISABILITIES: Government civil rights enforcement agencies and publicly-funded advocacy organizations should work more closely together and with adequate funding to implement effectively critical existing laws like the Americans with Disabilities Act, Fair Housing Act, Civil Rights of Institutionalized Persons Act, Protection and Advocacy for Individuals with Mental Illness Act, and Individuals with Disabilities Education Act, giving people labeled with psychiatric disabilities a central role in setting the priorities for enforcement and implementation of these laws.

CHAPTER 7

An Inter-Generational Vision for Effective Mental Health Services and Supports

As outlined in Chapters 3, 4, and 5, the fragmentation of the public mental health system has had a devastating impact on children, youth, adults and seniors with mental illnesses. And the disconnects between systems of care serving each of these populations have exacerbated these impacts further. Children and youth with severe emotional disturbance who do not get early screening and preventive services are more likely to find themselves poor and dependent on an adult mental health system that does not serve their needs. Unserved adults are likely to become unserved seniors.

Fundamental reform will require new thinking about how systems of care can invest—over a lifetime, if necessary—in adequate mental health services and supports that will allow children to live successfully with their families in the community, and will allow adults and seniors to seek recovery from the effects of mental illnesses and to achieve economic self-sufficiency.

Expanding the Resource Base

While there is no question that additional resources are needed to address America's mental health needs, policy makers must be educated about the "penny-wise and pound-foolish" manner in which mental health services and supports are currently delivered. As outlined in Chapters 1 and 2, the inability of the public mental health system to deliver preventive services and supports often leads people with mental illnesses into more restrictive and less humane settings, such as jails and prisons, homeless shelters and state hospitals. But that approach is substantially more expensive overall.

The Supreme Court's *Olmstead* decision also demonstrates how funds can be recaptured from unnecessary institutionalization. Recently, there has been renewed emphasis on reducing

the use of long-term hospital care, especially for people with the most severe mental illnesses.⁶⁵ Improved community treatments, such as psychiatric rehabilitation, consumer peer support and intensive case management programs, have become more widely available. Helping to fuel this movement are continuing concerns over the relative ineffectiveness and therapeutic limitations of inpatient care, including the dependencies it creates, and the fact that community care is generally no more expensive than institutional care.

Ironically, as a society, we may be paying much more for an ineffective patchwork of programs than we would for a comprehensive set of preventive services and supports. The cost of emergency hospitalization in a private hospital in an urban setting can be over \$1000/day. So-called "residential treatment programs" can cost as much as \$750/day. At \$350/day, even state psychiatric hospital care is quite expensive. People with mental illnesses who find themselves in state prisons or local jails cost taxpayers over \$100/day, and homeless shelters impose a similar tax burden. By comparison, proven models like supportive housing⁶⁶ cost much less, while providing many more opportunities for community integration.

The challenge here is to convince federal and state policymakers to adopt a longer budgetary view, and one that captures all of the costs of neglecting the public mental health system and the pressing needs of its consumers. A few communities have attempted such dramatic restructuring, with promising results. For instance, Vermont has secured a "Medicaid 1115 Waiver" to allow it to provide flexible and comprehensive services and supports through its

⁶⁵ Kamis-Gould, E., Hadley, T. R., Rothbard, A. B., et al: A framework for evaluating the impact of state hospital closing. *Administration and Policy in Mental Health* 1995; 22:497.

⁶⁶ See, e.g., Sam Tsemberis and Ronda F. Eisenberg, "Pathways to Housing: Supported Housing for Street-Dwelling Homeless Individuals With Psychiatric Disabilities," 51 *Psychiatric Services* 487-493 (2000); Houghton, *The New York/New York Agreement Cost Study: The Impact of Supportive Housing on Services Use for Homeless Mentally Ill Individuals*, Corporation for Supportive Housing (May 2001), available at <http://www.csh.org/NYNYSummary.pdf>.

Community Rehabilitation and Treatment (CRT) program, and has devoted state funding to provide housing and other services not reimbursable under Medicaid. As a consequence, each of the 3,200 adults in the CRT program has access to a broad range of supports that are tailored to his or her specific needs.⁶⁷ Similarly, in Los Angeles, the Village Integrated Services Agency is a comprehensive program for people with serious mental illnesses (clients are called members at the Village). The Village offers an array of options for members which supports individualized services in all quality of life areas (i.e. employment, housing, social, substance abuse, etc.). Staff focus on encouraging members' free choice of any menu option at any time.⁶⁸

Federal resources to support the expansion of community services required under *Olmstead* are available to states from several sources, including Medicaid's optional services for adults:

- targeted case management and rehabilitation;
- Medicaid coverage for services furnished in small community residential programs of fewer than 16 beds;
- Medicaid's array of comprehensive community services for children, mandated through the Early and Periodic Screening, Diagnosis and Treatment requirement of the law;
- Medicaid Home- and Community-Based Care Services Waiver; and
- expanding Medicaid eligibility through various options and waivers of federal rules—home- and community-based service waivers (Section 1915(c) of the Social Security Act), research and demonstration waivers (Section 1115), the option to cover people who are medically needy under Medicaid, and coverage of children with emotional disabilities under the "Katie Beckett" option (Section

⁶⁷ See Department of Developmental & Mental Health Services, DESCRIPTION OF PROGRAMS AND SERVICES, at <http://www.state.vt.us/dmh/>

⁶⁸ <http://www.village-isa.org/>

Despite the availability of such funding, many states have elected not to apply.⁶⁹

States also have the authority to allow certain health care providers to "presumptively" enroll children in Medicaid who appear to be eligible based on their age and family income. This can be done based on the family's declaration that its income is below the state's Medicaid income-eligibility guidelines. The child can then be provisionally enrolled in Medicaid and begin to receive services, while a full Medicaid application with the necessary information is prepared and submitted (this must be done by the end of the following month). States that fail to cover all eligible children, adults and seniors under Medicaid are losing the opportunity to secure federal matching funds for the home- and community-based services these people need.

Improving Access and Reducing Barriers to Securing Supports, Services, Treatment

Because cost of services is the most significant problem facing poor people with mental illnesses, expanding Medicaid eligibility and reimbursable services—concrete steps available to every state—are the most significant steps that can be taken to improve access to mental health services and supports for children, adults and seniors. The federal Medicaid program provides matching funds for such efforts, but many states experiencing budget shortfalls are loath to increase their own contributions, even when these leverage federal funds at very favorable levels.

The Surgeon General has outlined a program of action for improving access and reducing barriers for people of color and language minorities. These focus on coordinating early intervention and care to "vulnerable, high-need groups.... It is not enough to deliver effective mental health treatments: Mental health and substance abuse treatments must be incorporated

⁶⁹ See Bazelon Center for Mental Health Law, *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses*, available at <http://www.bazelon.org/undctord.pdf>.

into effective service delivery systems, which include supported housing, supported employment, and other social services.”⁷⁰

Barriers caused by geography are more difficult to address. Many rural areas simply lack the infrastructure to provide even basic mental health services and supports to any population. Rural practitioners are focusing more attention on integrating mental health services into traditional family practices, and on the use of telemedicine.⁷¹

Promoting Recovery

Today, unfortunately, the services and supports available to most people with serious mental illnesses are neither sufficient nor recovery-oriented. They are designed primarily to reduce the most obvious symptoms, minimizing the need for expensive hospitalization but promising little more. Driven at least in part by low expectations, these stopgap services rarely aim at promoting independence, gainful employment and fulfilling relationships—goals we all seek. And even these services are in extremely short supply, depriving many consumers of the only help, however inadequate, that might enable them to avoid unemployment, homelessness or contact with the criminal justice system.

But we have to avoid the temptation of defining success as the mere reduction of people with mental illnesses who are unemployed, homeless or in jail. Clearly, people who have been diagnosed with mental illnesses seek more than just abatement of their symptoms. They also want and deserve an opportunity to succeed in the community. What is most needed is a new vision that promotes the goal of recovery from mental illness, rather than the view that mental

⁷⁰ Mental Health: Culture, Race, And Ethnicity: A Supplement to Mental Health: A Report of the Surgeon General (2001), available at <http://www.surgeongeneral.gov/library/mentalhealth/cre/execsummary-6.html>.

⁷¹ See National Association for Rural Mental Health Web site, at <http://www.narmh.org/>.

illnesses are lifelong afflictions that need to be managed. Just as the national “welfare reform” debate pushed the country to conceive of a new way to move families from dependence to independence, the mental health community needs to rethink how resources can be allocated to promote independence of people with mental illness diagnoses.

Conclusion

Thirty years ago, the nation decried conditions on the back wards of state psychiatric hospitals, which were often referred to as “snake pits,” in which people with psychiatric disabilities were “warehoused” rather than helped to recover. Since then, through years of litigation, research and experience, public mental health systems have developed innovative models to support people with psychiatric disabilities in integrated settings in the community. But lack of visionary leadership and inadequate funding have prevented these models from “going to scale” in order to serve more people.

Instead, many public mental health systems are stuck in neutral gear, content that people with psychiatric disabilities will be “maintained” in the community, rather than supported in their recovery and helped on the road to economic self-sufficiency. In other words, the aspirations of many public mental health systems—as measured by actual programmatic and financial commitments rather than rhetoric—has not, for most people with psychiatric disabilities, changed much in 30 years. Instead of being warehoused on back wards of hospitals, many people with psychiatric disabilities today are warehoused in homeless shelters, jails and prisons and other isolated and segregated settings throughout our communities.

What is most needed now is a dramatically new vision of what people with psychiatric disabilities can achieve, if given the supports they need to succeed. That vision must start with the premise that recovery is possible and ought to be seen as an objective for every person with a psychiatric disability. The vision must also incorporate the principles of the ADA and the Supreme Court’s *Olmstead* decision, which declared that the unnecessary institutionalization of people with disabilities is a form of discrimination and that each state has an affirmative duty to move people with psychiatric disabilities out of isolated and segregated programs (whether in

hospitals or in the community) and into settings where they are truly integrated into community life. A final component of this new vision will require a commitment to fund effective supports and services and to fund enforcement of the rights guaranteed under the ADA, IDEA, Medicaid and other federal statutes.

The Federal Government can play an important role in establishing funding and other incentives for state mental health systems to adopt new models that support this vision and that are consistent with *Olmstead* and President Bush's New Freedom Initiative.

Appendix

Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the US Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts, and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the

- programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the Special Rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became the Americans with Disabilities Act. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of the ADA, improving assistive technology, and ensuring that those persons with disabilities who are members of diverse cultures fully participate in society.

Statutory History

NCD was initially established in 1978 as an advisory board within the Department of

Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.



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